Factors prolonging the time from onset of symptoms to start of treatment among smear positive tuberculosis patients in Sabah, East Malaysia

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ABSTRACT

A third of the world's population (2,000 million people) is infected with tuberculosis (TB)[1] and in 2000, there were an estimated 8.3 million new cases of TB.[2] After a few decades of neglect, it has re-emerged as a global emergency in 1993[1] when it combined with HIV. The two main control measures emphasised by World Health Organisation (WHO) are improved case detection and cure rates. High case detection level, especially of smear positive cases, is of great importance to decrease personal suffering, risk of death and limit transmission in the community. However, TB is also a social disease and many social aspects greatly influence TB control programme. One such aspect is the patients' understanding of their symptoms and their assessment of health care resources which further affect their health seeking behaviour.[3]

Malaysia is a country with intermediate burden of TB.[4] However, Sabah, one of the two states in East Malaysia has a notification rate of two and a half times that of the country's and contributes one third of the total cases.[5] Two studies have been conducted in West Malaysia on delay among TB patients but no such study has been done in East Malaysia. This research was conducted in 2 phases over a period of one year in 10 out of 23 districts in Sabah, East Malaysia. Phase 1 utilised a qualitative approach of face to face interviews to get a better understanding of the perception and health seeking behaviour of TB patients and those involved in their care. A total of 32 individuals (PTB patients, relatives and members of their communities) were interviewed. The findings also informed the questionnaire used in the cross sectional study in phase 2, conducted among 296 newly registered smear positive TB patients. The questionnaire was used to collect information on the different factors that affect the time period from onset of symptoms to start of TB treatment.

In this study, the percentage of patients who sought treatment after 30 days was 51.8% (95% CI: 45.9 - 57.8) and the median patient time period was 60 days. After adjustment of confounders using multivariate analysis, those

whose usual first treatment choice was a non-government health facility were twice as likely to have patient delay than those whose usual first choice was a government facility (Adjusted OR: 2.28, CI: 1.03 - 5.06). This is in contrast to a study conducted in Penang, West Malaysia where it was found that being male, those with lower than secondary education and misusing drugs were more likely to have patient delay. The median for doctor time period was 20 days and almost 43% of the respondents were put on treatment within 14 days of being seen by a medical doctor. In the multivariate analysis for doctor delay, those who had never used government facility, had chest pain and loss of weight were twice more likely to be associated with doctor delay. A repeat visit to the first provider was associated with an approximately 4 times greater risk of doctor delay than those who did not (AOR: 3.88, CI: 1.79 - 8.39). In the Penang study, West Malaysia, those whose first consultation were at government clinics had shorter doctor delay compared to those who consulted private practitioners.

Recommendations for improvement of current public health practice for the control of TB include ensuring greater awareness and adherence to existing guidelines on the management of TB patients by both government and private doctors. This will lead to high index of suspicion for TB among patients with cough thus ensuring timely sputum examinations. There is also the need for continuous health education on TB aim at raising awareness and at correcting misconceptions regarding cause, transmission and infectivity which will lessen stigma towards TB patients. The research findings on the patient and doctor delay can be used as baseline data to monitor improvement in health promotion activities and health service provision. This research found that around 43% of the respondents have no doctor delay of 14 days. A Quality Assurance Programme (QAP) can be developed to shorten doctor delay and such efforts would limit the period of infectiousness of the patient and thus the transmission to contacts.

Integrating statement about DrPH

DrPH programme would most likely appeal to someone with management and public health background. Its three components presented a wide range of opportunities to learn both formally and informally through classroom discussions, interaction with colleagues in the school and during the Professional Attachment and through conducting research. However, these exciting opportunities demanded patience, management skills and ability to learn and adapt.

The components of the DrPH programme are (1) Compulsory teaching units and three other units, (2) Professional Attachment and (3) Research. The compulsory teaching units consisted of (a) Evidence based Public Health Practice (2 units) and (b) Leadership, Management and Development. These units enabled me to consolidate previous understanding on public health and management and presented new ways of thinking on policy matters. The units on evidence based public health practice were particularly important in developing the skills on ways to influence policy makers through the understanding of processes in policy making and utilising evidence such as research findings. This understanding proved invaluable especially during my professional attachment and facilitated the analysis of policy making processes and the roles of different stakeholders. During the sessions on Leadership, Management and Development, there were many occasions to reflect upon my own management skills and leadership styles. In addition, there was the added advantage of interaction and discussion with other colleagues and lecturers who shared similar interests in management and public health.

Most DrPH students started with the compulsory units but due to late registration, I started with these three units:

a. Study Design: Writing a Study Proposal

b. Statistical Methods in Epidemiology (SME) and

c. Epidemiology & Control of Communicable Diseases (ECCD).

They were handpicked to help me later on with my research on TB. The first study unit allowed me to address issues surrounding research design while the ECCD unit helped with epidemiological issues and thinking processes. SME proved invaluable especially during data analysis.

My professional attachment took me for the first time to Cambodia where I was attached to CENAT, the National Centre for Control of Tuberculosis and Leprosy for 3 months. The strategies adopted in the TB Control Programme in Cambodia was similar to that in Malaysia with one obvious difference; many stakeholders were involved with the control programme including local and international non-governmental organisations. I decided to learn and write about the relationship and interaction between the different stakeholders. This stakeholder analysis provided a map of interest, power and influence of the various stakeholders. My professional attachment report also discussed policy making within the MOH and CENAT in relation to two important events; the health sector reform and the adoption of DOTS strategy. It also highlighted organisation design, culture and leadership issues and by dissecting these issues, a meaningful SWOT (Strength, Weakness, Opportunity and Threat) analysis was performed. The recommendations made did not address singular issue but the broader aspects of all the issues.

I proceeded with my field work soon after the professional attachment and spent 8 months conducting my research in Sabah, East Malaysia. I have worked in Sabah for the whole of my career life, from being a doctor in several hospitals to being a public health officer in several area health units. I have, in the past learned so much by being hands-on with my job and yet, learned so much more by doing my research on TB. It provided a different perspective of looking at life in general, gave insight to patients' lives which were rarely shared with outsiders and became a neutral spectator in the health provider-patient-community relationship. The process of doing research was an arduous task requiring patience, perseverance and dedication. My experience in conducting this research which involved both qualitative and quantitative approaches demanded the continuous process of making informed decision,

trying out new approaches and refining the understanding on theories and the thinking processes. Using both approaches gave a better picture of the health and health care seeking behaviour of TB patients. At its completion, there was an indescribable sense of achievement. However, despite spending three and a half years in such an extensive learning process, the words of Will Durant reflect my current sentiment, "Sixty years ago I knew everything; now I know nothing; education is a progressive discovery of our own ignorance."

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Acronyms and abbreviations

AIDS	Acquired Immune Deficiency Syndrome
A&E	Accident and Emergency
AOR	Adjusted odds ratio
BCG	Bacille Calmette-Guerin
CENAT	National Centre for TB and Leprosy Control
CI	Confidence Interval
CINAHL	Cumulative Index to Nursing & Allied Health Literature
DOTS	Directly Observed Treatment, Short-course
GDP	Gross Domestic Product
GNP	Gross National Product
GP	General practitioner
HIV	Human Immune Deficiency Virus
MDR	Multi-drug resistant
MOH	Ministry of Health
NGO	Non-governmental Organisation
OR	Odds ratio
QAP	Quality Assurance Programme
STD	Sexually transmitted diseases
SWOT	Strength, Weakness, Opportunities and Threats
TB	Tuberculosis
WHO	World Health Organisation

Acknowledgement

I am thankful to God for the many blessings in my life and oftentimes during my DrPH course, drew strength for the poem "Footprints in the sand" by Mary Stevenson, affirmed in the belief that He would and had carried me through the most trying periods of my life. I am also thankful to be blessed with family members, friends and individuals who have provided support in various forms throughout this period.

For my family members; my mother, my siblings, my nephews and nieces who understood my vision and provided invaluable support and help throughout my studies and research. Without their support, I cannot imagine the hardship I would have to go through.

For my supervisors; Punam Mangtani and Katherine Fielding who, during my DrPH have supported me through some indecisive moments and had given me full support and encouragement. In addition, they have provided me with guidance and first hand teachings which were invaluable as they provided me with the opportunity to think and reflect on the whole research process. I also thank them for their concern and care extended even when I had to complete the writing up back in Malaysia.

For the members of my advisory committee; Prof. Laura C. Rodrigues and Dr. Peter Godfrey-Faussett who despite their busy schedule took time to address my concerns on the research throughout the research process. I would also like to express my deepest gratitude to Karina Kielman who guided me through the qualitative study from the proposal to the writing stage. Thank you to Keith Branson for his invaluable help and computing support.

For my colleagues at the Sabah Health Department: Dr. Mohd. Yusof bin Ibrahim, the Deputy Director of Health, Sabah Health Department, Dr. Jiloris Dony, the Principal Assistant Director of the TB/Leprosy Programme, all Area Medical Officers of Health especially Dr. Maria Suleiman, Dr. Jenarun Jelip, Dr. Richard Avoi, Dr. Koay Teng Khoon, Dr. Asits Sanna and Dr. Shamsul Kamal.

Without their support, encouragement and help, it would have been near impossible to conduct the research as planned. I am also thankful to all their staff for the assistance rendered during the research especially to SN Moinis who became my research assistant for the first three months of the field work. I am grateful for the funding received from the Ministry of Health, Malaysia channelled to the Sabah Health Department which made it possible to conduct this research. The funding helped in hiring three dedicated assistants, Anzee, Linda and Fernandez.

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For the patients and their families; who opened the doors of their homes and shared the contents of their hearts and their experiences, I am forever grateful. I hope to become a better 'health provider' by this experience.

And finally, I would like to dedicate this achievement in memory of my late father whom we lost after a short period of illness in the year 2000. He grew up in a culture which did not place much importance on formal education for girls. Despite such upbringing, he made sure all his children especially the girls were educated and encouraged me to continue with the process of learning.

1 Chapter 1: Background and rationale

This chapter introduces the reason for the study on time period from the onset of symptoms to the start of treatment for TB patients and the need to identify possible explanatory factors for delay from onset of symptoms to presentation at health care provider (patient delay) and from consultation with a doctor to the commencement of treatment (doctor delay). It also describes the background for the research in terms of the epidemiology of TB, the DOTS strategy, the health care system and the TB Control Programme.

1.1 Public health problem

TB is a disease of ancient times; DNA analysis of tissue samples from mummified bodies and skeletal remains revealed that TB has inflicted humankind for more than 5000 years.[6] However, it continues to puzzle researchers and policy makers even today. This is because, although the organism responsible for TB has been known for 124 years and treatment for TB is available, TB remains a public health problem. TB is one of the most important yet neglected international health priorities.[7] The reduced numbers of TB cases in developed nations may partly contribute to this neglect. In most developed countries, a 'natural' decline in TB mortality over several decades occurred which could not be specifically attributed to any specific measures. However, due to scanty and unreliable data on TB mortality among developing countries, annual infection rates [a] for these countries have been used instead which show no 'natural' decline. However, if specific control measures such as early detection and compliance with treatment were taken, a decrease will be observed.[8] Today, TB is responsible for between 2.2 and 3 million deaths annually including at least 100,000 children throughout the world.[1] Eight million people a year are infected and a third of the world's population have already been infected.[1, 9]

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[a] Annual Infection Rate; this is calculated from prevalence surveys. Source: http://www.who.int/healthinfo/statistics/indtbincidence/en/index.html

The potential threat of TB was realised in the wake of the HIV epidemic. HIV is the strongest risk factor for TB in infected subjects.[10] Due to this and the absence of a solution to face the two combined diseases, in April 1993, WHO declared TB a global emergency.[11]

TB is a contagious disease. A person can be infected at any age and may remain so for a long time. About 5-10% of those infected will get TB disease and become infectious at some time in their lives. Over 90% of smear positive cases develop cough not long after the onset of disease.[2] However, cough is not specific to TB; it is also a prominent symptom in other respiratory tract infections and may be a constant irritation among smokers. The non-specific and non-threatening early symptoms of TB may have resulted in infectious persons not seeking treatment early.

Studies by Shaw et al, Grzybowski et al and Van Geuns et al have confirmed that patients with sputum smear positive pulmonary TB are more infectious that sputum negative PTB patients.[12] Therefore, it is more important to limit the duration of infectiousness of smear positive patients. Rouillon et al found that the proportion of contacts infected at the usual time of diagnosis of a sputum smear positive patient is around 30 to 40%.[12] This proportion would naturally be higher if the patient was left undiagnosed. The major factors that determine the risk of becoming exposed to tubercle bacilli include not just the 'pool' of infectious cases in the community but also the duration of their infectiousness and the number and nature of interactions between a TB case and a susceptible contact per unit of time of infectiousness.[12]

A shorter time period from onset of symptoms to presentation at health care provider and eventually to commencement of treatment is the aim in managing the control of TB. This will decrease suffering and the risk of death among the patients and those affected by his/her disease and in addition

decrease the risk of spread to contacts and the community. These effects are elaborated on here.

1.1.1 Suffering and risk of death

The sufferings of TB patients have been reported throughout the history of TB. Perhaps, the worse kind of suffering, aside from physical and economic, is rejection as a result of the stigma associated with TB which have been documented in many studies.[3, 13-18] This will be discussed in more detail in Chapter 2.

Case fatality rates among TB sufferers are high in the absence of appropriate chemotherapy. Studies in developed countries by Drolet, Lindhart, Galtung Hansen showed this rate to be consistently in the 50 to 60% range. The same 5-year study in India demonstrated that 49% of confirmed cases (smear and culture positive or smear negative but culture positive) died within 5 years[19],the majority of them actually died in the first 18 months, 33% recover spontaneously and the remaining 18% still have positive sputum[20, 21]. Case fatality rate for smear positive TB is even higher; Rutledge & Crouch and Lindhart noted this to be 66%[19] after a period of 4 years.[21] Two thirds of undiagnosed and untreated patients with smear positive TB die within 2 years of development of the disease.[22]

1.1.2 Financial burden on the patient and family

TB affects patients and their families economically in both direct and indirect ways. The direct cost mainly include the cost of treatment while TB indirectly affects the patients financially such as through loss of work. Several studies have assessed the financial burden of TB on its patients such as described here.

A study done in India where the mean monthly income of the study population was (Rupees)[b] Rs. 875 ± SD 1148 showed that the mean direct cost for getting treated for TB was Rs. 2052, indirect cost was Rs. 3934 and the total cost was

[b] One USD is approximately 40.7 Indian rupees

Rs. 5986 (USD171), which is 40% of the annual family income. The mean number of work days lost was 83. Sixty seven percents of rural and 75% of urban patients borrowed money on account of the disease and mean debts was estimated to be Rs. 2079. Among school children with affected parents, 11% discontinued their studies and an additional 8% took up employment to support their family.[23] In another small study in neighbouring Bangladesh, the mean financial loss to a village patient was estimated to be very high at USD245.[24] In Thailand, patients whose income was below the poverty line were particularly affected with out-of-pocket expenses exceeding 15% of the annual household income and a 5% reduction in income. Expenditures were met through bank loans (11.8%) and through sales of property (15.9%).[25] Among patients seeking treatment in Zambia, a mean total cost equivalent to 127% of their mean monthly income was incurred.[26] Clearly, TB is not only a disease among the poor but capable of creating a vicious cycle that further incapacitates the poor. It also affects the whole family, the quality of child care, education of children and contributed to child labour.[27]

TB has the greatest effect on the economically productive adults, who are also the parents, on whom rest the survival and development of children.[7] The considerable number of work days lost from an economically productive segment of the society will affect the productivity of the nation.

1.1.3 Risk of spread to contacts and the community

The best way to reduce transmission of tuberculosis infection and thus the number of TB cases is to cure smear-positive TB patients as they are reservoirs of infection. Various epidemiological studies have been used to quantify this transmission effect. An untreated case remains infectious for a long time as shown by a 5-year study in India in which 20% of bacteriological confirmed cases remained sputum positive after 5 years.[20] Styblo estimated that prior to the chemotherapy era, an infectious source can infect on average 20 persons during a 2 year-period of being infectious. Not all infected persons develop clinical TB. If the lifetime risk of becoming infectious

following infection is 5%, then two prevalent cases correspond to one incident case per year, each producing 10 successful transmissions per year.[12]

Several studies have reported the risk of close contacts such as family members, co-workers and fellow students becoming infected from undiagnosed TB patients. A case study report on 2 cases of TB in an office in Melbourne, Australia found that following an exposure to undiagnosed TB case for 4 months, at least 24% of the 195 co-workers were infected.[28] In a community college outbreak in Leicester, UK, an undiagnosed TB student resulted in 21 other cases in the college and 3 more among relatives.[29] In a study done in Los Angeles County, one in five TB patients sought treatment within 60 days and each had exposed an average of 8 close contacts[c] at home and work place to TB. [30] These figures suggest that close contacts either at home or place of work/study is more at risk of being infected compared to other community contacts.

By decreasing the risk of TB infection, there will be a reduction in the number of TB cases and a reduction in the danger from current sources of infection. This, in turn will reduce the number of future cases of TB.[31]

1.2 The importance of studying time period

DOTS strategy has been shown to be the most cost-effective strategy for the control of TB in many countries.[2] One of its elements is to detect as many cases as possible through the use of microscopic sputum examination. In order to be able to detect infected individuals, we rely heavily, due to resource constraints, on passive case detection. Passive case detection, in turn, depends on the health seeking behaviour of the patients which is determined by many factors such as the social, environmental and health culture of the community. Health culture can be defined as the understanding and

[c] The definition used for contact was person living in the respondent's usual sleeping place or who worked in the same room for more than 1 hour each day.

information people have from family, friends, and neighbours as to the nature of a health problem, its cause, and its implications.[3]

A person who has been inflicted with an illness needs to recognise that the symptoms he/she is having are indicative of a disease. He then develops the 'process' of illness response often described as health seeking behaviour. Health seeking behaviour is a term which is rooted in psychology and used in social cognition models. One such model is the Health Belief model which is elaborated on further in Chapter 3. According to Tipping and Segall, the utilisation of any formal system described as 'health care seeking behaviour', is influenced by socio-economic, sex, age, social status of female, type of illness, access to services and perceived quality of the service.[32] For TB, these factors often interact in a complex weave. People's confusion as to the implications of the TB symptoms, costs of transportation, the social stigma, the high cost of medication and patients' perception of clinic facilities as inhospitable all contribute to the complexity.[3]

Between men and women, there are often different patterns in health care utilisation. In some societies, women prefer visits to traditional healers[15, 33] prior to diagnosis or to self-medicate[34]. In some areas, women have problem accessing health services.[35] A study in Vietnam did not find any difference in access or utilisation but found that the women were not diagnosed as quickly as men; the mean doctor delay was 5.4 weeks for women compared to 3.8 weeks for men.[36]

Assessing time period from onset to consultation is, in fact, a way of understanding health and health care seeking behaviour. This time period could also be regarded as an indicator of transmission of TB in the community[37] though the extent of transmission in the community for those with prolonged time period is assumed rather than measured. The extent of transmission among close contacts has been described in section 1.1.3.

The time between onset of symptoms and consultation differs due to many factors that affect the health care seeking behaviours. Making an informed

cut-off point allows us to focus on those with unacceptably prolonged time period and assess whether the responsible factors are remediable.

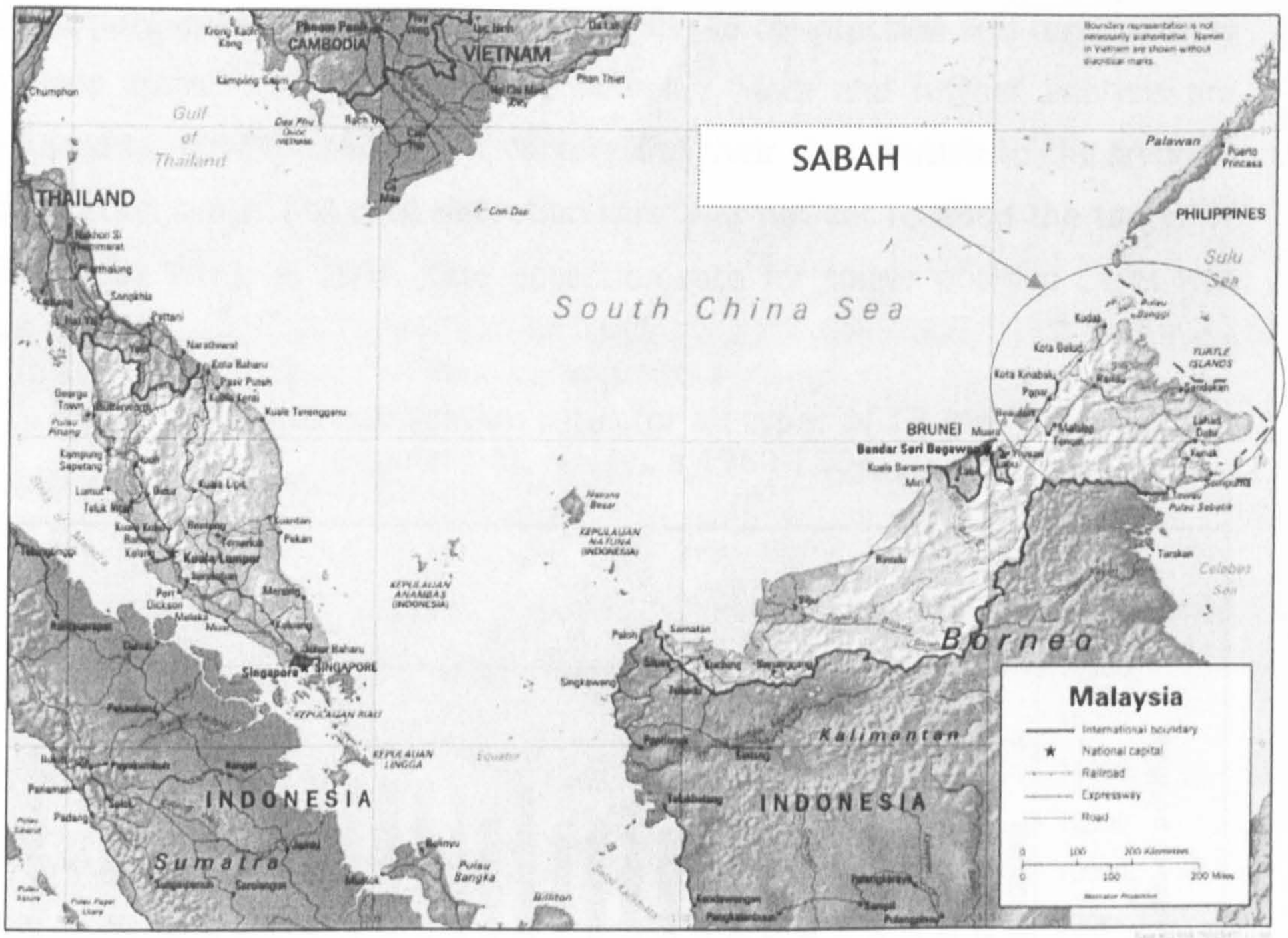
For TB, having chosen a particular health care provider does not mean the end of the problem. He/she is required to provide at least 3 sputum samples which have to be provided to the laboratory on two consecutive days and then to have a chest x-ray done. All the examinations may not be available at the clinic he/she first attended. Again, assessing the time period between consultation and diagnosis and eventually treatment will be a way to examine the pattern of health care utilisation and the efficiency of the health services. Similarly, by using a cut-off point for this time period allows us to focus on remediable factors in health services availability and uptake.

This aim of this study, conducted in Sabah in East Malaysia, was to understand the health and health care seeking behaviour among TB patients and to assess the various time periods from onset of symptoms to start of treatment and factors associated with delay in both attending and receiving treatment. The background for this study is described in the next section.

1.3 Country setting

Malaysia lies in the heart of Southeast Asia and comprises of the Malay Peninsula in the west and Sabah and Sarawak in the east. (Map 1) The country has a total land area of about 330 242 sq. km and a population of 26.6 millions in 2006.[38] Sabah and Sarawak are separated from the Peninsula by about 530 km of the South China Sea. Malaysia has 13 states and two federal territories. There are 3 major ethnic groups in West Malaysia; Malays, Chinese and Indians. In contrast, there are more than 50 ethnic groups in East Malaysia.[39]

Map 1: Map of Malaysia



Source: [40]

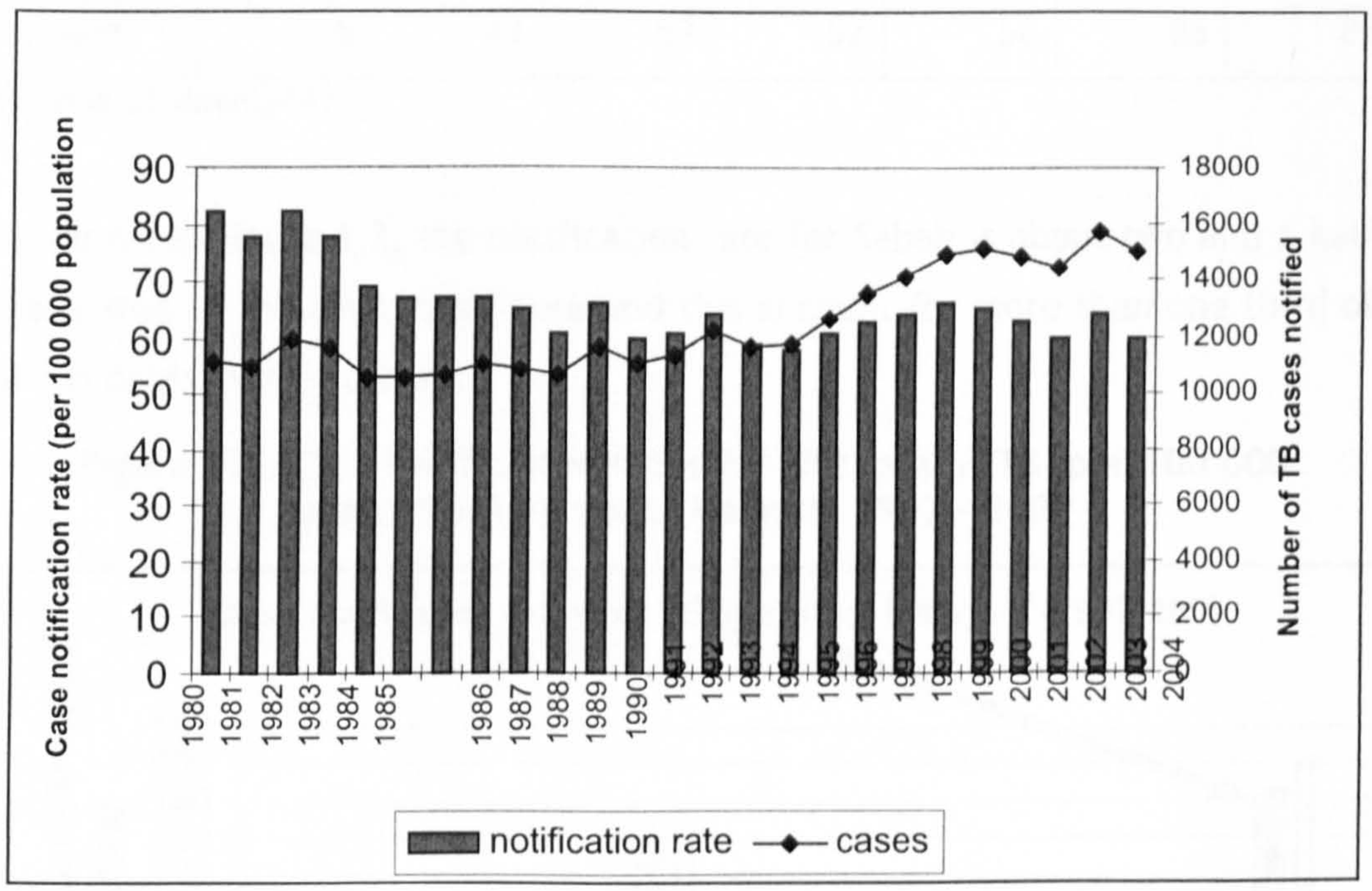
Malaysia is a developing nation with about a third of the population under the age of 15 years. As of 2001, approximately 58.1 percent of the population live in urban areas although there are variations among the states. Sabah currently has a population of about 2.6 millions and a population density of 35 people for every km^2. About 48% of the population reside in urban areas and about a quarter of the total population are in-migrants mostly from Indonesia and Philippines.[41]

1.4 The epidemiology of TB in Malaysia

TB is endemic in Malaysia and ranked by WHO as a country with intermediate burden of TB. It is a notifiable disease under the Prevention & Control of Infectious Diseases Act of 1988 (Act 342). Since the control programme was put in place in 1951, TB notification rates have been on the decline until about 1995 after which they started to rise again and started to decline again

in 2002 before rising again in recent years.(Figure 1.1) WHO has attributed the pattern to be due to several factors such as mobility of certain populations especially migrant workers, HIV-TB co-infection and rural poverty in some states such as Sabah.[42] However, data and further analysis are required to identify the specific factors and their contribution to the trend in notification rates. The case detection rate[d] has not yet reached the target of 70% set by WHO; in 2004, case detection rate for smear positive cases was 69%.[43]

Figure 1.1: Case notification rates for all types of TB (per 100 000 population), Malaysia 1980-2004



Source of data: [44]

Slightly more than half of all TB cases are smear positive. The notification rates of smear positive TB differs by age and sex. More males are affected than females. The notification rate is almost similar from birth until early

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[d] Case detection rate = annual new smear positive notification (country) / estimated annual new smear positive incidence (country)
The incidence of tuberculosis is an important measure to monitor the progression of the disease at country level. Estimates of incidence are derived from notifications to WHO; from disease prevalence surveys; or from surveys of the prevalence of infection in children, used to calculate the annual risk of TB infection (ARTI). Source: http://www.who.int/healthinfo/statistics/indtbincidence/en/index.html

adulthood after which a remarkable and widening difference is seen between the two genders. It is possible that the presence of migrant workers who tend to be male and from areas with high prevalence of TB infection may be a possible reason for this difference. The rates for both males and females are highest among those over the age of 65 years as shown in Table 1.1.[44]

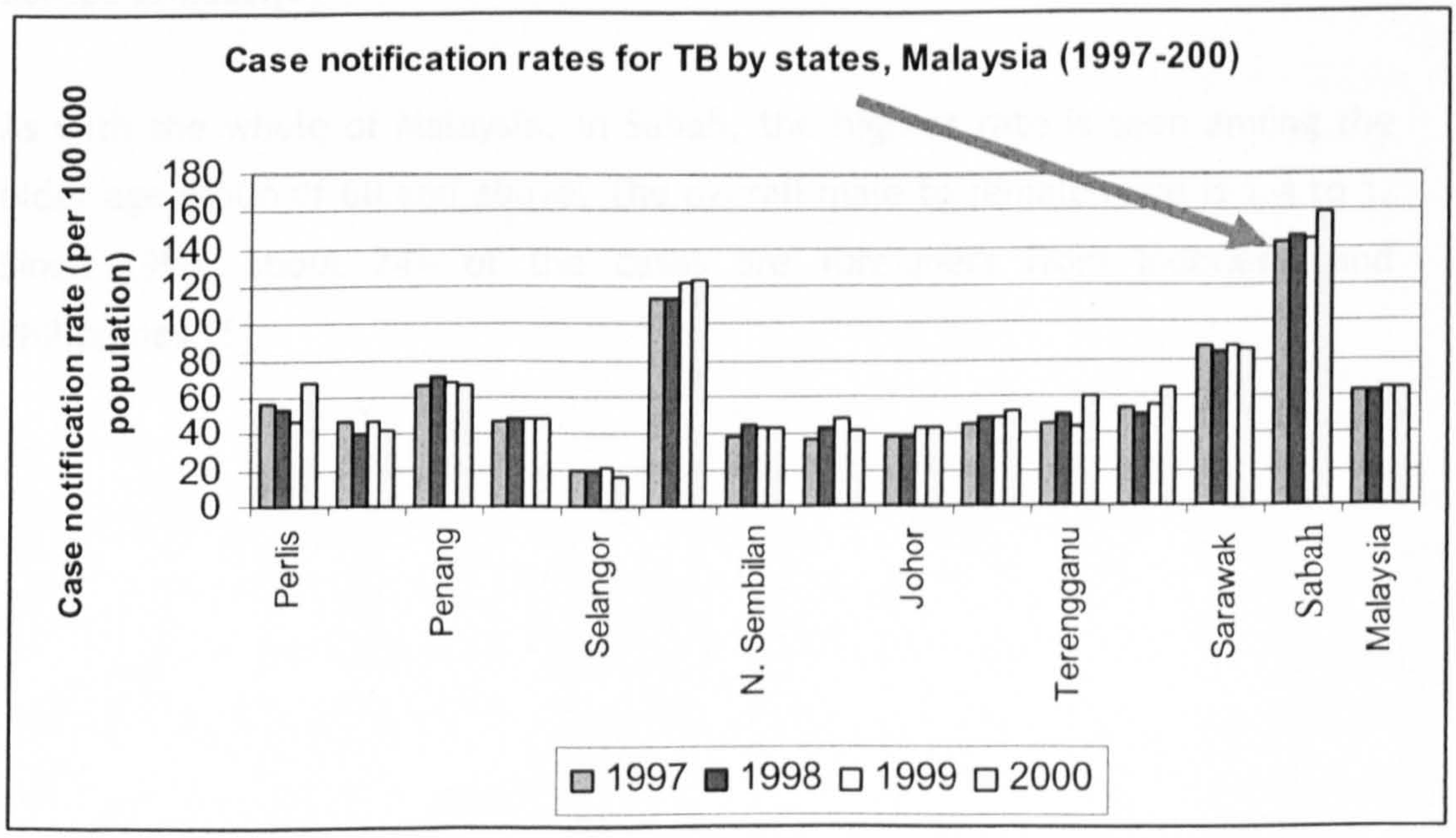
Table 1.1: New smear positive TB case notification rates (per 100 000 population) by age and sex, Malaysia, 2004

Age group (years)	0 - 14	15 - 24	25 - 34	35 - 44	45 - 54	55 - 64	65+
Male	5	51	108	131	149	200	296
Female	6	42	53	52	56	86	88

Source of data:[44]

As shown in Figure 1.2, the notification rate for Sabah is about two and a half times that of the country's figure and this account for more than one third of all TB cases in the country.

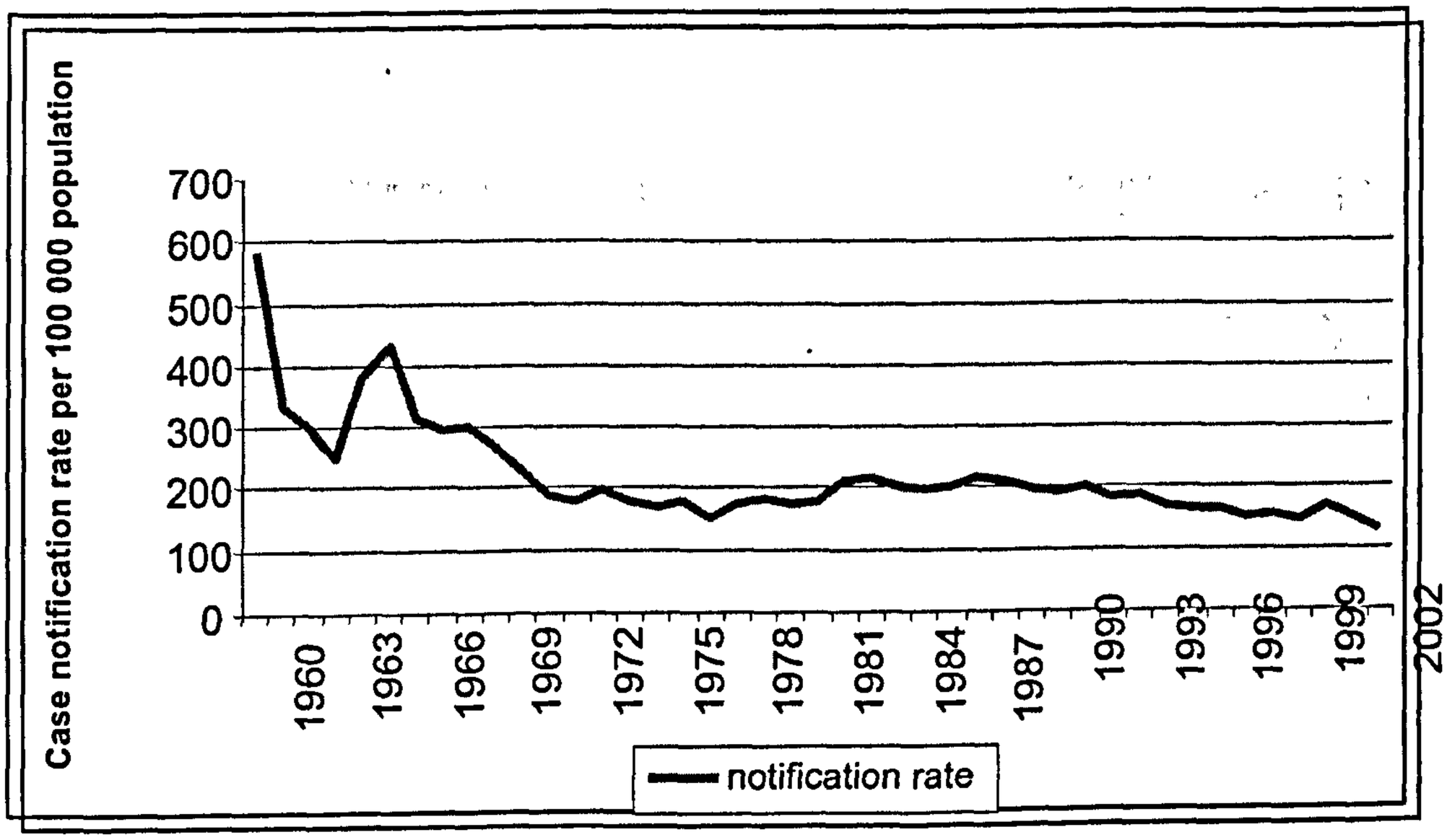
Figure 1.2: Case notification rates for all types of TB (per 100 000 population) by state, Malaysia 1997 - 2000



Source of data: Ministry of Health, Malaysia

In Sabah, the notification rate for the state was on the decline in the 1960s but has fluctuated between 100 and 200 per 100 000 population since the 1970s. (Figure 1.3)

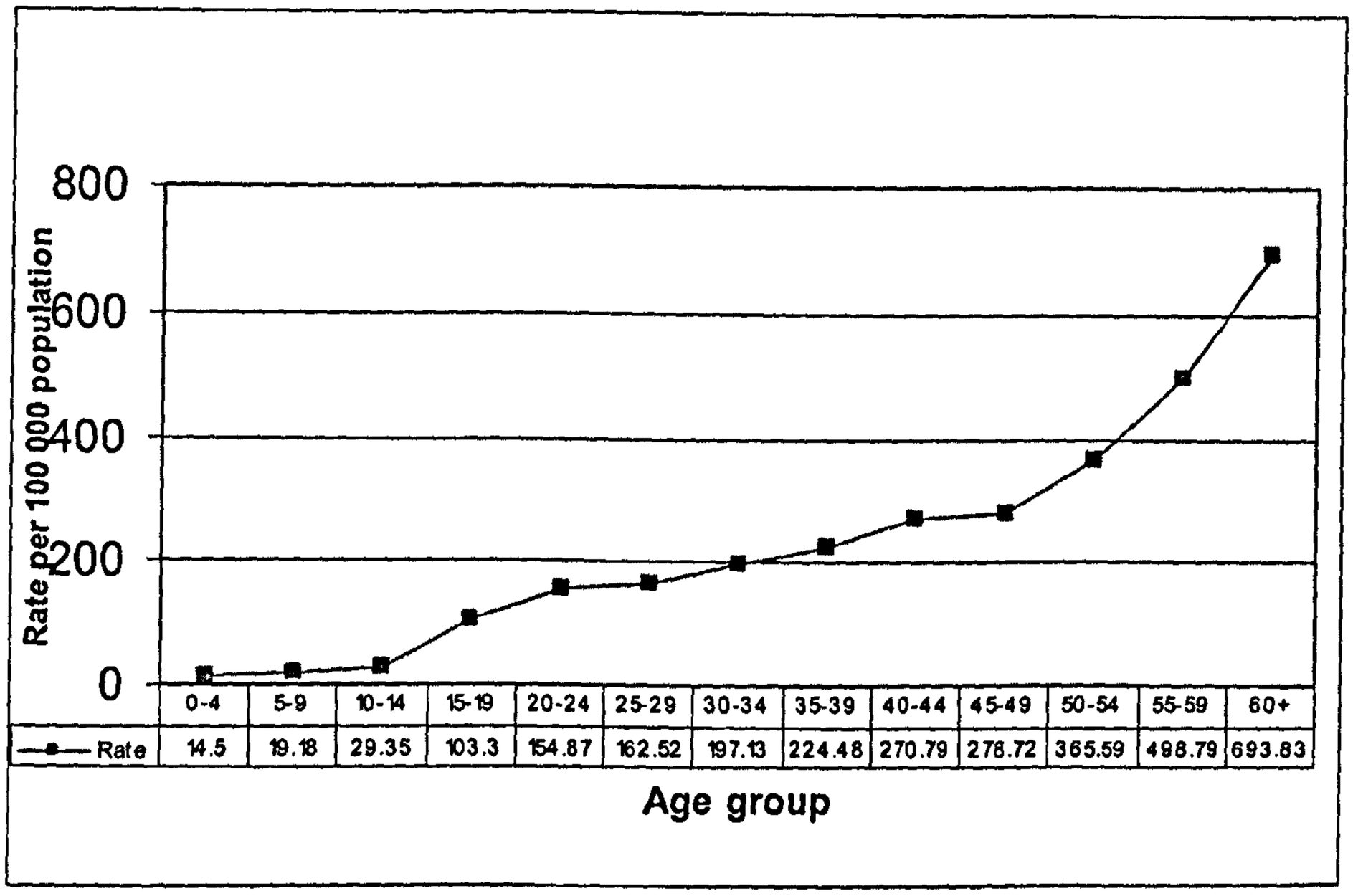
Figure 1.3: Case notification rates for all types of TB (per 100 000 population), Sabah 1960-2002



Source of data:[5]

As with the whole of Malaysia, in Sabah, the highest rate is seen among the older age group of 60 and above. The overall male to female ratio is 1.4 to 1. Since 1990, about 24% of the cases are foreigners from Indonesia and Philippines.[5]

Figure 1.4: Case notification rate for all types of TB (per 100 000 population) by age group, Sabah, 2001



Source of data:[5]

With regards to ethnic group, the combined group of the major indigenous groups (Kadazan, Dusun and Murut) had a notification rate of more than 250 cases per 100 000 populations for the past 10 years. The Chinese has a rate of less than 100 cases per 100 000 populations. Notification rates among foreigners (Indonesians and Filipino) ranges from 100 to 150 cases per 100 000 populations.[5]

1.4.1 HIV - TB Co-infection in Malaysia

The first HIV case in Malaysia was reported in December 1986. By 2000, the cumulative number of HIV cases was 38,340, of which 12.3% were AIDS cases and both numbers are rising. Data on HIV/AIDS have been collected through various surveillance activities such as routine surveillance and HIV sentinel surveillance. Currently, HIV testing which started in 1989, is targeted at 8 groups: antenatal mothers attending government facilities, blood donors, inmates of drug rehabilitation centres and prison, confirmed TB cases, STD

cases, patients with suspected clinical symptoms and contacts of HIV infected individuals.[42]

The prevalence of HIV is more in males than females. The most common mode of transmission is through intravenous drug abuse.[45] HIV prevalence among antenatal mothers and blood donors is less than 0.1%. In 2000, around 285 000 antenatal women were tested and only 0.03% were found to be HIV-positive. Among 330 000 blood donors tested in 1999, only 0.01% was positive.[45] In general, the prevalence of HIV in the adult population is less than 1%. WHO has estimated this prevalence to be 0.35% and has classified Malaysia as a country experiencing a concentrated epidemic, since HIV prevalence has been less than 1% among the general population, but consistently higher than 5% among injecting drug users over the past 10 years. [42]

HIV screening has been performed on all TB patients since 1990 and intensified in 1998.[46] In 1990, only six cases of TB with HIV co-infection were reported out of the total 10,873 cases notified (0.05%) [47] and since then has been on the rise reaching 900 cases out of 14,389 registered TB cases (6.2%) in 2002.[42] The prevalence of HIV among adult TB patients (15-49 years old) was 2.5% in 2004.[43] TB-HIV co-infection is less of a problem in Sabah. In 2001, the accumulated numbers of HIV patients were 120 and in the same year, only three TB patients were found to have HIV infection.[48]

1.4.2 Multi-drug Resistance TB (MDR-TB)

MDR-TB is fortunately low in Malaysia. In 2004, only 0.1% of the new TB cases were MDR-TB while there were none among previously treated TB cases.[43] The MDR-TB situation in Sabah is also low; in 2001, the accumulated number of MDR cases was 13.[49] The most common cause for the emergence of resistant strains in Malaysia is incomplete or inadequate treatment.[50]

1.5 The TB Control Programme in Malaysia

1.5.1 DOTS Strategy

The most cost-effective strategy for TB control of TB in many countries has been proven to be DOTS strategy.[2] Borgdorff et al have reviewed various studies on the various interventions in TB control and concluded that with WHO directly observed treatment, short-course (DOTS) around US$5-40 per disability-adjusted life year (DALY) was gained in a middle income country in the absence of HIV.[51]

Malaysia adopted the DOTS strategy in the 1999.[42] In Sabah, over the past few years, better facilities for diagnosis in terms of equipment and personnel have been put in place in many health centres. This was in line with the practice of decentralizing diagnosis from hospital to health centres. Strict adherence to treatment regime as outlined in the national guideline is observed by both government and private practitioners. Directly observed therapy-short course has also been employed where ingestion of the tablets is observed by treatment supervisors; health personnel, family members or health volunteers. The final element in DOTS strategy is monitoring and reporting of treatment outcome. In 2003, a new information system, the TB Information System (TBIS) has replaced the previous system with the revision of existing databases and reporting formats. This system has allowed for data to be stored in a more systematic and efficient way in the form of Registry and Report books. These books are maintained at the District Health Office by Health Inspectors and at the treatment centres by Medical Assistants. As a result of all these steps, in 2002, the coverage for DOTS in Sabah was 93.8% with variability among the districts from 81.9% to 100%.[46]

1.5.2 The general structure of health care system

There is extensive network of health facilities in the country. Primary health care is available through existing health care facilities such as health centres and community clinics while secondary and tertiary care is provided in both public and private hospitals. A community clinic is the basic unit of the health

care system covering a population of approximately 2000. It is often manned by community nurses and focuses on the Maternal and Child Health programme. However, basic curative services can also be provided. Sputum examination is not routinely done in these clinics. However, in the rural areas where the incidence of TB is high, the nurses are trained to collect the sputum specimen and prepare the slides for examination at the nearest health clinic. Once treatment for TB is started at the health centres, it can be continued at the community clinics.

Larger units, health centres covering a population of 7 to 10 thousands, provide curative services by the Primary Care Unit in the health centres and also implement all health programmes including the TB control programme. They are manned by Medical Assistants, nurses, laboratory technicians and Assistant Public Health officers. In Sabah, some health centres especially in urban areas and those with heavy work load have doctors.

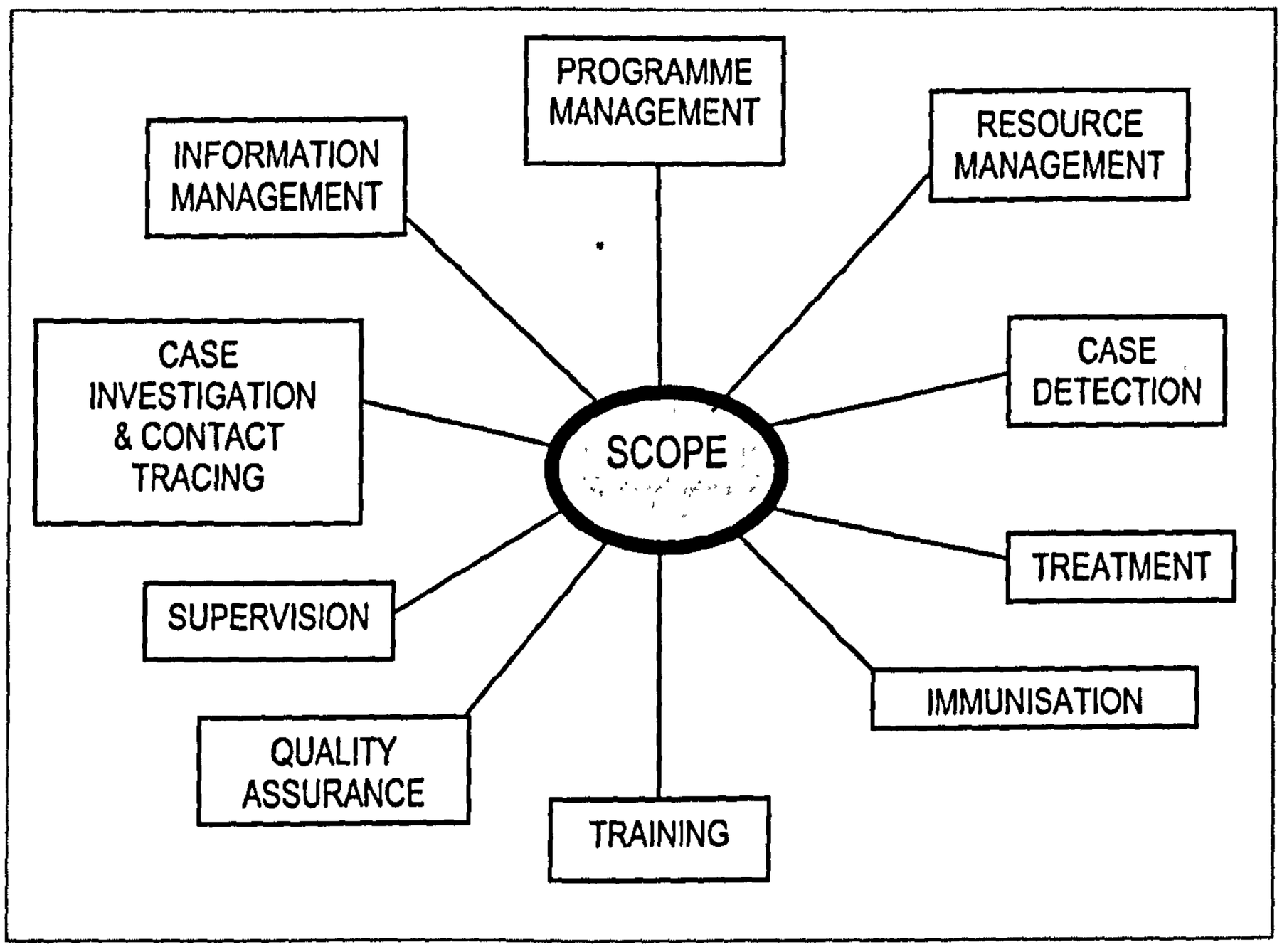
The health cost is heavily subsidized by the government. There are no charges for local citizens for out-patient care which includes laboratory investigations and treatment at the health clinics. There is a small fee for out-patient services at government hospitals, approximately USD0.26 for Malaysians. Non-Malaysians have to pay approximately USD3.9 which is equivalent to a 'simple' consultation with a private doctor. The hospitalisation cost for notifiable diseases such as TB is free for both Malaysians and non-Malaysians.

Human resources are still a problem in the country but are more pronounced in Sabah. In 2006, there are only 998 doctors in both public and private clinics thereby resulting in a doctor: population ratio of 1:2938. Throughout Sabah, there are 19 public hospitals, 11 private hospitals, 82 health clinics, 187 community clinics, 18 Maternal and Child Health clinics and 8 mobile clinics.[52]

1.5.3 TB Control Programme in Sabah

The scope of the TB Control Programme in Sabah is shown in Figure 1.5. Case detection and treatment are but two of the 10 elements in the control efforts. Due to limited human resources as highlighted in 1.5.2, the wisdom in integrating a vertical programme like TB into the main public health activities as was done in the 1990s becomes apparent. A considerable amount of cooperation and networking occur with other units such as the Maternal and Child Health Unit for immunisation and Primary Care Unit for case detection and treatment. These are two different Units working side by side in the health centres.

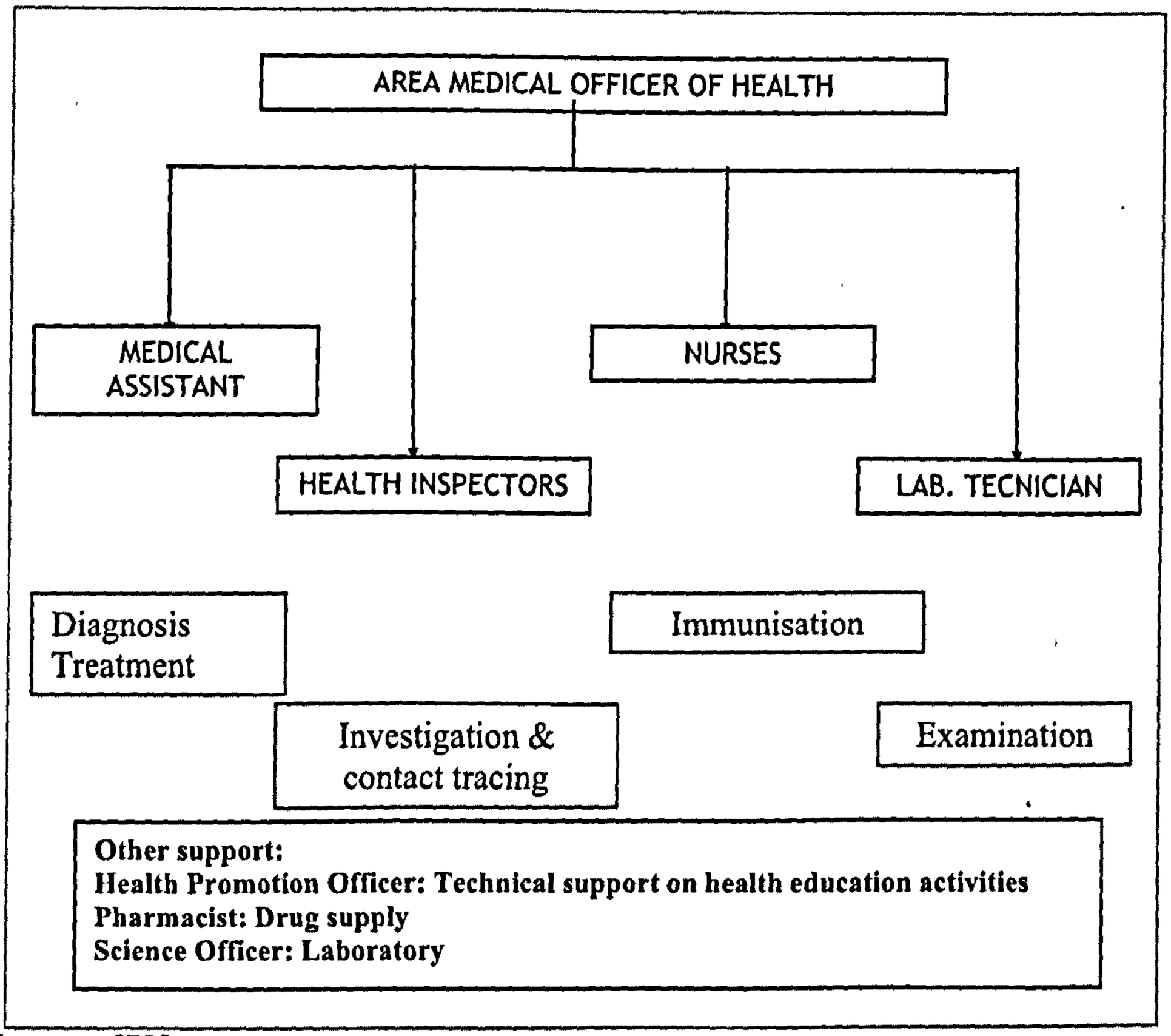
Figure 1.5: Scope of TB Control Programme in Sabah



Source: [53]

There is a TB Control Unit in every district. The overall responsibility for the implementation of TB control efforts rest with the Area Medical Officer and his/her team in every district which consist of the personnel shown in Figure 1.6 who are based at the District Health Office. The organisation chart for TB Control programme in a district is shown in Figure 1.6.

Figure 1.6: Organisation chart for TB Control Programme in a district in Sabah



Source: [53]

The Health Inspector in-charge of this unit is responsible for maintaining the TB Registry for the district as well as for case investigation and contact tracing. The Senior Medical Assistant supervises all the Medical Assistants at the health facilities in term of curative services. A laboratory technician is responsible for ensuring that sputum microscopy is performed in a timely way and accurately. Slides are sent monthly to the Central Laboratory in Kota Kinabalu, state capital of Sabah, for quality control. Feedback is sent to the district within 2 months and any discrepancies in terms of bacterial load of the sputum are corrected in the monthly report and patient record. Ensuring uninterrupted supply of anti-TB drugs is the responsibility of a Pharmacist. Anti-TB drugs are available at all health facilities throughout Sabah. The Health Matron oversees the immunisation programme where all newborns

regardless of place of birth or personnel conducting the birth, are given BCG immunisation at birth.

Supervisions and training of all staff are carried out by the team from the District Health Office. Health education to the patients is provided at all health facility by all levels of staff. Technical support is provided by the Health Education Unit also based at the District Health Office. This TB organisation structure at the district level mirrors the one that exists at the state level.

1.6 Rationale for the thesis

When Robert Koch announced the discovery of *Mycobacterium tuberculosis* to the Physiological Society of Berlin on the 24th March 1882, the excitement was not on his discovery but at the accompanying certainty that the real fight against the disease could begin.[7] Several decades after the discovery of chemotherapy with no sign of TB being eliminated, DOTS strategy became the 'buzz' word and welcomed globally. Almost a decade after it was introduced; only a gradual decline of TB is seen in many parts of the world such as in South East Asia and Western Pacific regions while in other parts such as Africa, a continuous rise is still evident.[54]

In Malaysia, there is little change in notification rate among smear positive patients; 48 per 100 000 population in 2000 down to 46 per 100 000 in 2004.[55] Sabah, in East Malaysia, contributes one third of the total cases in the country. Its notification rate for all cases has been hovering between 100 to 200 per 100 000 population for almost a decade now.[5] TB control efforts in past years have been concentrated on setting up the infrastructure such as making available diagnostic facilities in almost all health facilities and training staff to handle the added responsibility. In Sabah, TB is still in its 'pure' form, treatable using the current chemotherapy regime. MDR-TB is still very low and HIV-TB co-infection is relatively low. In many parts of the world such as Sub-Saharan Africa and in countries of former Soviet Union, the

struggle towards elimination has been made harder as a result of HIV and MDR. Thailand has a high prevalence of HIV/AIDS and due to higher awareness of HIV/AIDS compared to TB and the similarity of TB and AIDS symptoms, longer delay for TB was seen because patients were afraid to be diagnosed with AIDS.[56] For Sabah, a 'window of opportunity' currently exists to lessen the burden of TB in the community with relatively little HIV driving TB rates. To date, there has not been any research on TB in Sabah with the objective of determining the time period from onset of symptoms to effective treatment. It is the hope that the findings of this study will contribute to the shortening of this infectiousness period and thus the transmission in the community.

The importance of ensuring that infectious TB individuals are detected and put on treatment has been emphasised in section 1.2. The duration of infectiousness is an important factor in the control of TB. TB is a social disease and many factors affect the time from seeking treatment to being treated. The objectives of this research are to assess the duration of time from onset of symptoms to treatment and factors which influence the various time periods.

Patients are often blamed when they 'delay' in presenting for treatment or when they do not comply with treatment. In terms of time frame, there is no general consensus as to what constitutes 'delay'. Although I will be using the word 'delay' as used and reported in other studies, in this research, the time between identified milestones will be referred to as time period. The word 'delay' would mean that a cut-off point has been decided which dichotomised the time period into 'no delay' and otherwise.

Two studies conducted in West Malaysia in the 1990s, have analysed delay in TB diagnosis. Both studies were conducted at urban hospitals among the 3 main ethnic groups in West Malaysia [57, 58] and found the median patient time period to be 2 weeks. In both studies, the median doctor delay was longer: 5 weeks[58] and 7 weeks[57]. The median total time period differed slightly between the studies: 12.5 weeks[57] and 12 weeks[58]. The authors of

these papers suggest that doctor delay was associated with seeking private practitioners who often did not suspect TB.

No study on time periods from onset to consultation and to commencement of treatment has been conducted in East Malaysia. In the West Malaysia study in Penang[58], an urbanised island setting, 34% of the patients came 1 month after onset of symptoms and 27% came after 2 months. It is very likely that these figures will be higher in Sabah. This research involved both out-patient and public health clinics and different ethnic groups than those in the West Malaysia studies.

This study aimed at assessing the various time periods; from onset to consultation (patient time period) and from consultation with a doctor to commencement of treatment (doctor time period). It also identified explanatory factors for patient and doctor delay using pre-determined cut-off points which are 30 days for patient delay and 14 days for doctor delay. In addition, explanatory factors for extreme patient delay (> 90 days) and doctor delay (> 60 days) were also determined. This was to determine the factors which may explain why patients remained in the community and thus posed as possible source of infection.

Due to the lack of research on TB in Sabah, the decision was to conduct the research in two phases; the first phase used qualitative approaches while the second, quantitative methods. The first phase was to explore the perception and health seeking behaviour with regards to TB. This was done using face to face interviews with TB patients, relatives and key informants such as village headmen, traditional healers and health staff. By using this approach, a better understanding of other social aspects of TB can be gained such as issues related to stigma and effects of TB on its patients. The findings from this qualitative study also informed on the questionnaire to be used in the second phase in terms of definitions, range of answers and structure of the questionnaire.

The second phase was a cross sectional study which involved newly diagnosed PTB patients who fulfilled pre-set inclusion criteria in 10 selected districts in Sabah. A pre-tested questionnaire was administered to these respondents to identify patient and doctor time periods and explanatory factors associated with patient and doctor delay.

1.7 Outline of the structure of the thesis

This research details the time period between several milestones in the course of TB: the onset of symptoms, to first consultation, to diagnosis and finally to treatment in Sabah, East Malaysia. It also explores the factors that affect this time period. The rationale behind the research and an outline of the methods used is described in Chapter 1. It also describes the setting for the study; the epidemiology of TB, TB Control Programme and the health care structure in Malaysia. Chapter 2 focuses on literature reviews in which studies on time from onset of TB symptoms to start of treatment and perceptions of TB are summarised. In addition, the issues with stigma as a result of TB are also reviewed. Relevant issues surrounding time period such as the definitions of time period and 'acceptable' delay are also discussed in Chapter 2 and possible explanatory factors for the various forms of delay are presented in the same chapter. The explanation of the conceptual framework on health and health care seeking behaviour for TB can be found in Chapter 3. The first part of the study which utilised qualitative methodologies such as in-depth interviews to gather information from TB patients, relatives and members of the community on issues such as health seeking behaviour, understanding of TB and stigma are documented in Chapter 4. The quantitative study is presented in five chapters: Chapter 5 is on the methods, Chapter 6 describes the characteristics of the respondents and symptoms experienced, Chapter 7 describes the results on explanatory factors for patient delay, Chapter 8 presents results on doctor delay and the discussion is presented in Chapter 9. Recommendations and conclusion are detailed in Chapter 10.

2 CHAPTER 2: Literature Review

This chapter describes the literature review on time period and delay from onset of symptoms to start of treatment, perceptions of TB and stigma. Specific issues are drawn from the review namely the non-standardised definitions, factors responsible for delays and the 'over-use' of the term 'delay'. The importance of reviewing studies on the perception of TB is in its relation to health and health care seeking behaviour; for example a belief that TB is caused by 'evil' spirits could explain why a visit to a spiritualist was made. Stigma has often been linked with delay in getting treatment among TB patients. A basic understanding of why that is so, is relevant. The objectives of the literature review is to review articles with respect to (a) definitions of delay, (b) definitions of acceptable delay, (c) factors associated with delay, (d) perceptions of TB and (e) stigma.

2.1 Methods for literature review

A search was carried out to assemble the published literature (with no language restriction) on time period and/or delay using databases Medline, CINAHL (Cumulative Index to Nursing & Allied Health Literature) and Cochrane. The keywords used were "TB, epidemiology, ethnology, prevention and control, transmission" AND "delay" or "time period". Grey literature and unpublished studies were also included as well as literature known to experts in the field, daisy chaining from articles, books and reviews and hand searching through particular journals such as the International Journal of Tuberculosis & Lung Disease and Social Science and Medicine Journal. All studies which either specifically addressed the issue of delay or as part of a larger research question were eligible. Similarly, this method was also applied for studies on perception of TB and on stigma using the appropriate keywords; i.e. "TB" AND "perception" or "stigma".

2.2 Results on delay

The literature search identified 262 articles on delay through Medline out of which 69 were eligible based on examining the titles and abstracts. The full manuscripts of these citations were examined and only 38 studies in 29 countries were identified to be relevant and summarised in Appendix 1. All but two were cross sectional studies, the other two were cohort studies [59, 60]. Nineteen studies used patient questionnaire while others utilised data from registry or medical records and focus group discussions. Thirty one of them used median to describe the time period, three used the mean while another four used different cut-off points such as 4 weeks in the Zambia study[18] and 20 days in Mumbai study[61]. Only five studies reported on results of multivariate analysis of either Cox proportional hazard model or logistic regression. [30, 62-65]

2.2.1 Issues with definitions of delay

Different definitions for delay have been used by various authors. Despite the different terminology used for patient delay, this time period generally refers to the time lapse between the onsets of symptoms to first consultation with any type of health care provider. With regards to this, there were differences between the studies in two areas: the presenting symptoms for which treatment was sought and the type of health provider. (Table 2.1) For example, some studies were specific in using pulmonary or chest symptoms [66] while others used the onset of symptoms such as cough, fever, lethargy, loss of weight which are suggestive of TB [67]. In terms of health care provider, some used the consultation to medical personnel[e] as the end point [30, 60, 62, 66-68] while for the others, the end point was consultation with any health care providers[f] [61, 69].

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[e] Medical personnel are trained doctors.
[f] Health care providers include both practitioners of modern and traditional medicine.

For the other time periods such as doctor, health service, the differences were in relation to the final event; either diagnosis or treatment. Some used the first point as the time of consultation and the commencement of treatment as the end[60, 62, 64, 65, 70] while for others, the time to a definitive diagnosis[66]. (Table 2.1) One study referred the term 'diagnostic delay' to the period between onset of symptoms to initiation of treatment.[26] This in turn would affect the definition of total delay where the end point could be either the time of diagnosis or commencement of treatment. One study used 'hospitalisation' as the end-point.[63]

In addition, some studies further break the period from medical consultation to start of treatment in 2 phases; from consultation to diagnosis (physician delay) and from diagnosis to treatment (treatment delay).[67]

Table 2.1: Definitions for delay

Main Author	Country	Definitions
	PATIENT DELAY	
Demissie, M.[66]	Ethiopia	Time interval from appearance of major pulmonary symptom to first visit at a medical facility.
Masjedi, M.R.[67]	Iran	Time between onsets of symptoms to first medical consultation.
Diez, M. [62]	Spain	
Rajeswari, R.[71]	South India	
Lawn[72]	Ghana	
Hooi, L.N.[58]	West Malaysia	
Paynter, S.[60]	London, UK	
Yamasaki-Nakagawa, M.[33]	Nepal	
Ward, J.[70]	Australia	
Wandwalo, E.R.[73]	Tanzania	
Aoki, M.[74]	Japan	
Yimer, S.[75]	Ethiopia	
Golub, J.E.[59]	Maryland, USA	
Chiang, C-Y.[76]	Southern Taiwan	
Gagliotti, C.[77]	Italy	
Odusanya O.[68]	Nigeria	

Main Author	Country	Definitions
Lienhardt, C.[69] Steen, T.W.[65]	The Gambia Botswana	Time between onsets of symptoms to any health care provider.
Guneylioglu, D.[78]	Turkey	Patients' application interval: time interval between onset of symptoms and first doctor's visit
Tamhane, A.[61]	Mumbai, India	Seeking care after 20 days of onset.
Chakraborty, A.K.[79]	India	Interval between chest symptoms and action taken by patients for relief. (any provider)
OTHER FORMS OF DELAY		
Needham, D.M.[26]	Zambia	Diagnostic delay: time from symptom onset to initiation of therapy.
Odusanya O.[68]	Nigeria	Doctor delay: time between visit to first facility and the chest clinic.
Demissie, M.[66]	Ethiopia	Health service delay: first consultation to diagnosis.
Masjedi, M.R.[67] Diez, M.[62] Rajeswari, R.[71]	Iran Spain South India	Physician delay: time taken by physician to diagnose TB Treatment delay: time after diagnosis before treatment.
Tamhane, A.[61]	Mumbai, India	Treatment delay: treatment initiated after 14 days of first consultation.
Chakraborty, A.K.[79]	India	Health system delay: interval action taken by patient and final diagnosis as TB. Total mean delay: interval between chest symptoms and final bacteriological diagnosis.
Lawn, S.D.[72] Yamasaki-Nakagawa, M.[33] Aoki, M.[74]	Ghana Nepal Japan	Doctor delay: from first consultation until diagnosis. Total delay: from onset of symptoms to diagnosis.
Hooi, L.N.[58] Paynter, S.[60]	West Malaysia London, UK	Doctor delay: from consultation to commencement of treatment.
Lienhardt, C.[69]	The Gambia	Health provider delay: from first visit to health care provider to first visit to LTI (Leprosy/Tb Inspectors).

Main Author	Country	Definitions
		Diagnosing facility delay: from first visit to LTI to start of treatment. Total delay: from onset of symptoms to start of treatment.
Ward, J.[70]	Australia	Health care system delay:
Yimer, S.[75]	Ethiopia	difference in days from the date
Golub, J.E.[59]	Maryland, USA	of first relevant presentation to
Chiang, C-Y.[76]	Southern Taiwan	a medical practitioner and the date of starting treatment (or
Gagliotti, C.[77]	Italy	diagnosis if no treatment was
Wandwalo, E.R.[73]	Tanzania	given)
Steen, T.W.[65]	Botswana	Diagnostic delay: difference
Date, J. [80]	Yemen	between the date of first consultation and date of diagnosis. Treatment delay: difference between the date of diagnosis and the initial treatment date.

When comparison is made with other studies, one should be aware of the different definitions for these time periods and different units of measurements. Standardised definitions would ideally help data comparison.

2.2.2 Acceptable delay

Different approaches have been used to define "delay" and/or acceptable delay. In some studies, the median was used to dichotomise patients into shorter or longer delay.[62] Therefore, one should be careful in making comparison across studies as the time lapse or median may be different in each studies. Patient delay in West Malaysia is defined as greater than 30 days from onset to consultation[58] but in Spain, patient delay was defined as greater than 22 days.[75] Following the same argument, a factor which resulted in delay in one setting may not have the same association in another. As mentioned, some studies used the mean to define delay.

More importantly, there is no general agreement as to what an 'acceptable' delay for patient or doctor time periods should be. Some authors, for example in West Malaysia consider an acceptable delay between first consultation and start of treatment as one month or less[58] or in Zambia, between onset of symptoms and first consultation as 4 weeks [18] or 30 days in Ethiopia and Nigeria [66, 68] or between onset of symptoms and initiation of treatment as 1 month[81] or 2 months in Japan [74]. One study suggested that the definition of a reasonable delay in a given situation will depend on the prevalence of TB and the nature of the health care system.[70] For example, in that study conducted in Lusaka, Zambia, delay of more than 4 weeks for patients with cough was taken to be significant as the national guidelines were that patients with cough of more than 3 weeks duration should be investigated further.[18] In Tanzania, a consensus among general practitioners and a specialist chose '30 days' as maximum acceptable patient delay and '10 days' for health system delay. These decisions were based on medical knowledge and the socio-economic conditions of their patients.[73] In the California study, 60 days from onset to medical consultation was defined as 'clinically significant delay' based on previous study which showed that exposed domestic contacts of active TB patients frequently showed signs of infection after 2 months of exposure.[30]

In a similar way, one might need to take partly into consideration the location of diagnostic facilities. In some health care settings, consultation, diagnostic facilities and treatment centres could be in different locations, as in the Gambia[69]. In Lagos, patients had to be referred to the Chest Clinic for diagnosis and treatment and doctor delay meant that this period between referral and diagnosis exceeded 15 days.[68]

2.2.3 Factors affecting delay

Different factors affect the different time periods for TB case finding. Generally, it is thought that patient delay is mostly due to patient factors and once a patient is seen by a health care provider any delay is due to the health care

provider. While this may be true, patients may not be able to abide with the procedural demands made by the health care provider and therefore may also contribute to delay. Patients are required to provide a minimum of three samples submitted consecutively over 2-3 days, for sputum examination which may require them to attend another facility. Patients, due to whatever reasons, may not be able to do so within the required time and therefore contribute to the health care provider delay.

Factors associated with health services such as lack of diagnostic facilities, practices and staff attitudes were not assessed in most of the studies reviewed. Therefore, some elements of health care provider which may be responsible for delay were not highlighted. Studies found different factors affecting delay and some of these factors need to be interpreted within the context of the research setting, for example, the case of someone who does not speak English such as an immigrant in New York and has health care delay[64] has no relevance in a setting where in-migration of people with different mother tongues is not an important issue.

a. Patient delay

Table 2.2 summarises factors associated with patient delay and more details can be found in Appendix 1. Studies have found that both men and women may delay, presumably due to their health care seeking behaviour. Older age group tend to delay more. For example, in New York, those age 55 to 64 years old were 10 times more likely to delay than those aged 15 to 24. The profiles of those who delay seem to lean towards those who are less privileged: those with low economic standing [30, 82], lower education level [71],[73], and rural residents [73] and those who live far from health facility with long travelling time [18, 71, 73, 75, 83]. In a study in Yemen, the author suggested the reason illiterate patients had delay was because they do not question the diagnosis given to them by the doctors. If they were told they had 'common illness', they were reluctant

to seek further evaluation whereas literate patients were more sceptical and only accept their diagnosis in the presence of definite evidence such as laboratory results.[80]

In terms of health utilisation: generally those who seek non-government health facilities and those whose perceptions of the health services were poor tend to have patient delay. Those with social problems also tend to delay seeking treatment. These associations are to be expected in most circumstances. In developed and low prevalence settings, local born and those with no index TB case seem to delay, presumably due to lack of awareness of the disease. However, other factors are not easy to explain as the reverse is seen such as increasing severity of disease, or having haemoptysis associated with delay when they are expected to reduce delay.

Table 2.2: Factors affecting patient delay

No	Category	Factors associated with longer patient delay
1	Gender	• Male: Penang, Malaysia[58] and Teheran, Iran[67] • Female: Mumbai, India[61] and Lusaka, Zambia[26]
2	Age	• > 33 years old: London, UK[60] • greatest delay in the 35-64 age group: Spain[62] • > 45 years old: Mwanza, Tanzania[73] and Ethiopia[75] • < 45 years old: South India[71] • 55- 64 years old: New York, USA[64] • Older age: Maryland, USA[59] and Hunan, China[83]
3	Economic	• Unemployed: California, USA[30] and Ukraine[82] • Poor economic status: Istanbul, Turkey[78] • Low income: South India[71] and Hunan, China[83] • Employed in private sector: Ukraine[82]
4	Geography	• Rural setting: Mwanza, Tanzania[73] • Distance from health facility: Lusaka, Zambia[18] and Hunan, China[83] • 2 km from health facility: South India[71] • > 1 hour of walking from health facility: Ethiopia[66] • > 10 km from health facility: Mwanza, Tanzania[73] and Ethiopia[75]

No	Category	Factors associated with longer patient delay
5	Education	• Illiteracy: South India[71] • Lower than secondary education: Penang, Malaysia[58], Maryland, USA[59] and Luzaka, Zambia[26] • Lower than primary education: Mwanza, Tanzania[73]
6	Social problem	• Drug user: Penang, Malaysia[58] • Alcoholism: South India[71] • Those who felt ostracised because of illness: Manila, Philippines[84]
7	Perception of health service	• Poor perception of health service: Lusaka, Zambia[18]
8	Symptoms	• Haemoptysis: Ethiopia[66] and Hunan, China[83] • Cough and weight loss: Ukraine[82] • Increasing severity of illness: Lusaka, Zambia[18] • Self rate health as fair or good: Kweneng, Botswana[65] • No respiratory symptoms: Maryland, USA [59] • Presentation of constitutional symptoms: Spain[62]
9	Health seeking behaviour	• Visit to government facility as first provider: South India[71] • Seek folk therapy: Hunan, China[83] • Prior attendance to private clinic: Lusaka, Zambia[18] • Believe they could treat themselves: California, USA[30] • Visit to traditional healer: Mwanza, Tanzania[73] • Self treatment: Ethiopia [75]
10	Knowledge	• Uncertain about where to get care: California, USA[30] • Poor or no knowledge about TB: Ethiopia[66] and Mwanza, Tanzania[73]
11	Others	• Born in a low prevalence country: London, UK[60] • Have no index: Istanbul, Turkey[78] • Primary language other than English: New York, USA[64] • Migrant and stayed ≤ 3 years: Italy[77]

b. Health service delay

Risk factors for health service delay were almost similar to patient delay. (Table 2.3) In addition, in terms of symptoms, those who presented with no cough[26]

or cough of shorter duration[71, 77] had health service delay which is what one might expect. Repeated encounters would also result in delay.[26] In developed settings, again, those born in low prevalence country[60] and non migrant[70] would have health service delay due to low index of suspicion among the health care providers.

Table 2.3: Factors affecting health service delay

No	Category	Factors associated with longer health service delay
1	Gender	• Female: Zambia[26],Ghana[72], Hunan, China[83], Manila, Philippines[84], India[79], South Africa[63]
2	Age	Increasing age: Queensland, Australia[70] and Maryland, USA[59]
3	Geography	• > 5 km from health facility: South Africa[63] • > 2 km from health facility: South India[71] • > 30 minutes walking distance to clinic: Ethiopia[66] • Rural residence: Ghana[72] • Village without hospital: Kweneng, Botswana [65]
4	Education	• Low level of education: Zambia[26], Yemen[80] and Hunan, China[83], India[79]
5	Marital Status	• Being married: Kweneng, Botswana[65]
6	Social problems	• Homelessness: New York, USA[64] • Alcoholism: South India[71] • Ever drank alcohol: South Africa[63] • Stigma of disease: Hunan, China[83] • Had been a migrant worker: South Africa[63]
7	Symptoms	• Positive smear: Zambia[26] • Absence of cough: Zambia[26] and New York[64] • Shorter duration of cough: South India[71] • Self rate health as poor or very poor: Kweneng, Botswana[65] • History of asthma: Maryland, USA [59] • Cough only: Southern Taiwan[76] • Cough of less than 1 month: Italy[77]
8	Health seeking behaviour	• Those who present to general practitioner(GP) than to others: Zambia[26], South India[71], London, UK[60] and Ethiopia[75] • Visit to traditional healer: Zambia[26] and Kweneng, Botswana[65] • First consultation with other than chest physician:

No	Category	Factors associated with longer health service delay
		Italy[77] • Women who visited traditional healer: Nepal[33] • First visit to health post: Ethiopia[75] and Kweneng, Botswana[65] • Village with no hospital: Kweneng, Botswana[65] • Those who presented to hospital rather than clinic or GP: South Africa[63] • Believed disease caused by bewitchment: South Africa[63] • Sought folk therapy: Hunan, China[83]
9	Knowledge	• Prior health education on TB: Hunan, China[83] • Believed TB caused by bewitchment: South Africa[63]
10	Health service practice	• >6 instances of encounter: Zambia[26] • Outpatient diagnosis of TB: Zambia[26] • No chest x-ray at first visit: New York, USA[64] • Those needing hospitalisation: Ghana[72] • Rural facility: Mwanza, Tanzania[73]
11	Others	• Born in low prevalence country: London, UK[60] • Increasing length of stay (Australia): Queensland, Australia[70] • Non migrant: Queensland, Australia[70] • Speak English: Maryland, USA [59] • Has insurance: Maryland, USA [59] • Migrant: Italy[77]

c. Total delay

Most factors that were associated with longer patient and health service delay were also responsible for total delay. (Table 2.4) Again, the unexpected association between some of the symptoms such as haemoptysis and total delay is not easily explained.

Table 2.4: Factors affecting total delay

No	Category	Factors associated with longer total delay
1	Symptoms	• History of recurrence: Spain[62] • Presence of respiratory symptoms: Spain[62] • Presence of pulmonary and extra-pulmonary disease: Spain[62] • Clinical picture not fully manifested: Italy[85] • Those with loss of weight and haemoptysis: Pakistan[86] • Cough only: Southern Taiwan (Chiang)
2	Age	• 25 - 34 years old: The Gambia[69]
3	Health seeking behaviour	• GP as first provider: Italy[85] and Pakistan[86] • First visit to health post: Kweneng, Botswana[65] • Visit to traditional healer: Kweneng, Botswana[65]
4	Geography	• Rural residence: Ghana[72]
5	Others	• STD treatment during the last 3 years: Kweneng, Botswana[65] • Registered on Out-patient card: Kweneng, Botswana[65]

2.3 Perception of TB

There are several studies on the perception of TB as shown in

Table 2.5 which have provided useful insight into the 'uniqueness' of TB compared with other infectious diseases. (Details in Appendix 2) Most of the findings revealed that TB is often perceived outside the bio-medical explanatory model that view TB as a disease caused by *Mycobacterium tuberculosis* and transmitted by aerosol droplets. The understanding of the perception of TB allows for negotiations and compromise for both health provider and patients and their families towards the success of care and control of the disease. For example, when patients do not believed that TB was caused by an infectious agent and insists on seeking traditional medicine, the compromise could be that they could still try other medicine but not to default taking the anti-TB drugs.

Table 2.5: Studies on perception of TB

Country, First author	Ethnic group	Findings
New York State. Carey JW, USA[87]	Vietnamese refugees (non TB participants)	▪ TB is an infectious lung disease Risk factor for TB: ▪ Hard manual labour, smoking, alcohol consumption and poor nutrition. ▪ All infection inevitable leads to disease
Vietnam. Long NH.[88]	Vietnamese (TB and non TB participants)	▪ TB dangerous and contagious disease cause by germs. Four main types of TB: (1)*'Lao truyen'* (hereditary TB), handed down from older generations through 'family blood', regardless of sex (2) *'Lao luc'* (physical TB), caused by hard work, more men are affected (3) *'Lao tam'* (mental TB), caused by too much worrying, more women are affected (4) *'Lao phoi'* (lung TB), dangerous, caused by TB germs, transmitted through the respiratory system and more men are affected.
Ethiopia. Vecchiato NL. [89]	Ethiopians (non TB participants)	▪ Do not regard tubercle bacilli to be the cause of TB. Prefer to seek ethno-botanical remedies.
Chiapas, Mexico. Alvarez-Gordillo GC.[90]	Mexicans (TB patients)	Perceived causes of TB: contagion via food utensils, excess work, malnutrition and cold as well as other causes unrelated to person-to-person contagion.
South Africa. Edginton ME.[91]	Rural South Africans (TB patients and community)	▪ TB is the result of breaking cultural rules such as not abstaining from sex after the death of a family member and after a spontaneous abortion. Remedy can only be obtained from traditional healers.
Aceh Province, Sumatra, Caprara A., Indonesia[92]	Achehnese	TB is represented by a semantic network of illnesses, partly transmissible, partly related to specific phenomena affecting the individual, such as *'terbuk'* (poisoning) or *'trouk'* (fatigue produced by hard work) and are not considered contagious. TB is attributed to (a) germ (b) socio-economic conditions; (c) transgression of social rules and (d) poisoning and the

Country, First author	Ethnic group	Findings
		influences of supernatural powers.
Manila, Philippines. Auer C.[84]	Filipinos (TB patients) - semi structured interview	Perceived causes of TB: ▪ Drying sweat on the back, smoking, microbe, drinking alcohol, dirty environment, sleeping on cold floor, fatigue, working too hard, frequent pneumonia, lack of food, poverty, to be near a TB case, inherited, many sex partners.
Kenya, Liefooghe R.[93]	Kenyan tribes (TB and non TB participants)	Perception of TB: Dangerous disease, highly contagious and difficult to cure.
West Malaysia, Liam CK.[94]	West Malaysian (TB patients)	Attributed symptoms to: ▪ common cold ▪ 'weak' body ▪ overwork ▪ asthma, lung cancer, diabetes mellitus, pneumonia, TB, dengue fever, heart failure ▪ cigarette smoking ▪ effect of an abortion ▪ a spell put on them by someone
Orange County, CA, Rubel AJ [3]	Mexicans (TB patients)	Symtoms associated with ▪benign conditions *gripe* (grippe) or *bronquitis* (bronchitis) ▪ a folk illness, susto ▪ fatigue and weight loss due to hard work and lack of sleep

As shown in Table 2.5, despite current knowledge on TB as to its cause and mode of transmission, in societies with linkages to their cultural roots, the understanding of TB is 'richer' and diverse. Whether they are right or wrong is secondary to the fact that in order to engage TB patients and the community, such interpretations should be acknowledged.

2.4 TB and stigma: untangling the web

Stigma has often been seen as a barrier to seeking treatment and responsible for sending TB underground. Few researchers have tried to assess stigma and most have used qualitative approaches. Researches by Erving Goffman, a sociologist,

on face-to-face interaction or micro-sociology have made popular the concept of stigma. He defines stigma as *"a process by which the reaction of others spoils normal identity."* He describes three different types of stigma as shown below: [95]

a. Abomination of the body; the various physical deformities
b. Blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs and dishonesty
c. Tribal stigma of race, nation and religion; these being stigmas that can be transmitted through lineage and equally contaminate all members of a family.

Although there were differences between the three types of stigma, the main concept was that of a "spoilt identity". Often the individual is blamed and yet in reality, other people such as the community, the state and global institutions are responsible in producing and ameliorating stigma. The concept of stigma should be discussed within a collection of concepts such as that of contagion, defect and disability and made relevant across many cultures and contexts.[96] TB is said to be a good example where the two concepts of stigma and contagion merge into each other thereby confusing the picture as to whether one fears TB because it is contagious or that it is a disease that sets one apart or both. In the absence of fear of contagion, stigma is lessened or nonexistent. Among the Vietnamese, one type of TB; *'Lao luc'* (physical TB) is caused by hard work and not contagious and therefore families did not isolate the patients.[88]

However, in general, the relationship between TB and stigma throughout the history shares a common thread running through; that of fear and isolation. It began with fear of its fatality as noted by Hippocrates around 460 BC. Hippocrates also warned his colleagues not to visit patients in the late stages of the disease, not because of anything but that the inevitable deaths would damage their reputations.[97] In 'A New Theory of Consumption' by Benjamin Marten in 1702, he wrote *"It may be therefore very likely that by an habitual*

lying in the same bed with a consumptive patient, constantly eating and drinking with him, or by very frequently conversing so nearly as to draw in part of the breath he emits from the lungs, a consumption may be caught by a sound person...I imagine that slightly conversing with consumptive patients is seldom or never sufficient to catch the disease."[97] This led to the avoidance of close and frequent contacts with TB patients. Sometimes, everyone in the family was inflicted and TB was thought to be hereditary. This led to a kind of 'familial stigma' which further led to isolation, separation and even divorce.

Following the discovery of the tubercle, the early recommended treatment for TB was rest, fresh air and good food. As a result, sanatoriums mushroomed to make this treatment available. In fact, Styblo had suggested that isolation in sanatoria of highly infectious TB patients had reduced the risk of infection in the community.[22] The sanatoria have long gone but this form of isolation is still being replicated within families and communities even today.

With the discovery of anti-TB drugs, TB patients can be cured and it is now possible to see the long term effects of TB on a person's life. During their illness, TB patients may lose a lot of weight, sometimes leaving just skin over the bones. After treatment, they can became a shadow of their former selves and never regain their former strength. This can be seen as a form of 'deformity' or 'disability' which could lead to stigma. Their quality of life can be compromised as noted by Chamla among the Chinese patients in his study.[98] Today, TB is feared for a familiar reason; the absence of cure, this time due to HIV, MDR-TB[g] and of late, XDR-TB[h]. Fear of TB has come full circle.

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[g] MDR-TB is a specific form of drug-resistant TB due to a bacillus resistant to at least isoniazid and rifampicin, the two most powerful anti-TB drugs.[99. http://www.who.int/tb.

[h] XDR-TB is TB that is resistant to any fluoroquinolone, and at least one of three injectable second-line drugs (capreomycin, kanamycin, and amikacin), in addition to MDR-TB. This definition of XDR-TB was agreed by the WHO Global Task Force on XDR-TB in October 2006.[99. Ibid.

Macq et al have reviewed studies examining stigma and TB.[100] He defined studies as being about two classical types of stigma (enacted and perceived) and the potential negative impact of stigma on TB Control Programme. In addition, the determinants of TB stigma were often unfounded beliefs about transmission or health staff attitude. Finally, studies also found that TB stigma was often associated with patient's characteristics which were potential sources of discrimination such as gender, poverty and co-infection with HIV.[100]

Understanding the features of stigma is invaluable as interventions can be focussed on each feature. For example, fear of TB can be allayed by convincing the community that TB is curable. Addressing the misconception that TB is a familial disease will lessen the effect of stigma. Counselling TB patients may improve the general health of the patients. However, in certain societies where discrimination towards certain groups such as the women or certain ethnic groups exists, merely unpacking the features of stigma will not be sufficient in influencing health and health care seeking behaviour.

The understanding from the literature of factors affecting delay, perceptions of TB and stigma were used to build a conceptual framework for this research. This conceptual framework on factors influencing health care seeking for possible TB symptoms is presented in the next chapter.

3 CHAPTER 3: A conceptual framework for health and health care seeking behaviour

This chapter outlines the conceptual framework for health and health seeking behaviour among TB patients. The conceptual framework (Figure 3.1) was constructed using the following four models. These models of health-related actions, often constructed by social scientists, were developed to analyse how people view and react to health-related events.[101].

- Health Belief Model
- Health Care Utilisation Model
- The 'four As'
- Pathway model

On their own, they are insufficient to explain the health and health care seeking behaviour among TB patients, hence the use of several models, the choice of which was informed by previous studies on health seeking behaviour, time period and delay. For example, studies from developing countries such as Tanzania[73, 75] and Ethiopia[75] suggest that living far from health facility affect the time period between onset of symptoms and seeking treatment. As such, the health care utilisation model was included as the patient's perception of the severity of an illness as explained by the Health Belief model was insufficient to explain when and how the patient would seek care. Although the principles of the four As (Availability, Accessibility, Affordability and Acceptability) are already enshrined in the health care utilisation model, the specifics are important to consider when discussing health care access. The pathway model include the different options for action as well as the role of other people in the decision making process for seeking care. All models are explained and their usefulness and limitations discussed here.

3.1 Health Belief model (HBM)

The core of the conceptual framework is derived from the HBM. This model, originally developed by social psychologists Hochbaum, Rosenstock and Kegels in the 1950s is a systematic method to explain and predict preventive health behaviour. The model was influenced by the theories of Kurt Lewin which states that it is the world of the perceiver that determines what an individual will and will not do.[102]

This model hypothesised that the perceived susceptibility to a disease, perceive severity of that disease and perceived benefits of preventive actions minus the perceived barriers to taking those action explained the likelihood of an individual taking appropriate actions.[103] The HBM is popular in health education programmes even today but often its practical application did not yield the results or change in actions. Good, a medical anthropologist, is of the opinion that the main reason for this is because the HBM assumed a narrow conception of culture and human action.[103] Firstly, the assumption was that human behave rationally towards the goal of positive health; that he is able to weigh the benefits of particular behaviours and be able to act freely. Health culture was only as important as to the extent of its contribution to the decision-making process. The studies which revealed that those with increasing severity or haemoptysis tend to present late[66, 83], suggests the first assumption may be incorrect. The second assumption is that lay medical culture was of a lower standard to that of biomedical knowledge.[103] These have been the limitations of the HBM and although it is relevant to TB in terms of outlining the various factors that influence decision to seek care, it does not identify what triggers a person to take action.[3]

3.2 Health Care Utilisation Model

This model, based on the works of sociologists Andersen and Aday, was included as it was specifically developed to investigate the use of biomedical health services.[104] This model provided a system perspective which integrates a range of individual, environmental and provider-related variables

associated with the decision to seek care.[105] It organizes factors related to health care service utilization into three categories: (1) predisposing factors such as attitudes toward service use; (2) enabling factors that promote or inhibit use; and (3) need factors of the patients which necessitates health care use.[104] By using this categorisation, the relevant factors in relation to health care seeking behaviour among TB patients were postulated and shown in Table 3.1.

Table 3.1: Health care utilisation factors

Predisposing factors	Age, gender, education level, experiences and attitudes towards health services, knowledge about illness, community pressure
Enabling factors	Financial resources, availability of health services, accessibility, social support
Need factors	Severity of illness, number of sick days, need for outside care

One can see that this model complement the HBM by the addition of enablers and need factors which are important in the decision making towards health care use.

3.3 The 'four As'

The 'four As' model has been widely used where distance (social and geographical) and economic aspects were emphasised as key factors for access to treatment.[106] The four As refer to availability, accessibility, affordability and acceptability. (
Table 3.2)

Table 3.2: 4As factors in relation to access to health care

Availability	Refers to the geographic distribution of health facilities, pharmaceutical products etc.
Accessibility	Includes transport, roads, etc.
Affordability	Includes treatment costs for the individual, household or family. A distinction is made between direct, indirect and opportunity costs.
Acceptability	Relates to cultural and social distance. This mainly refers to the characteristics of the health providers - health workers' behaviour, gender aspects (non acceptance of being treated by the opposite sex), excessive bureaucracy etc.

This model was included as it identified specific aspects of access to health care use.

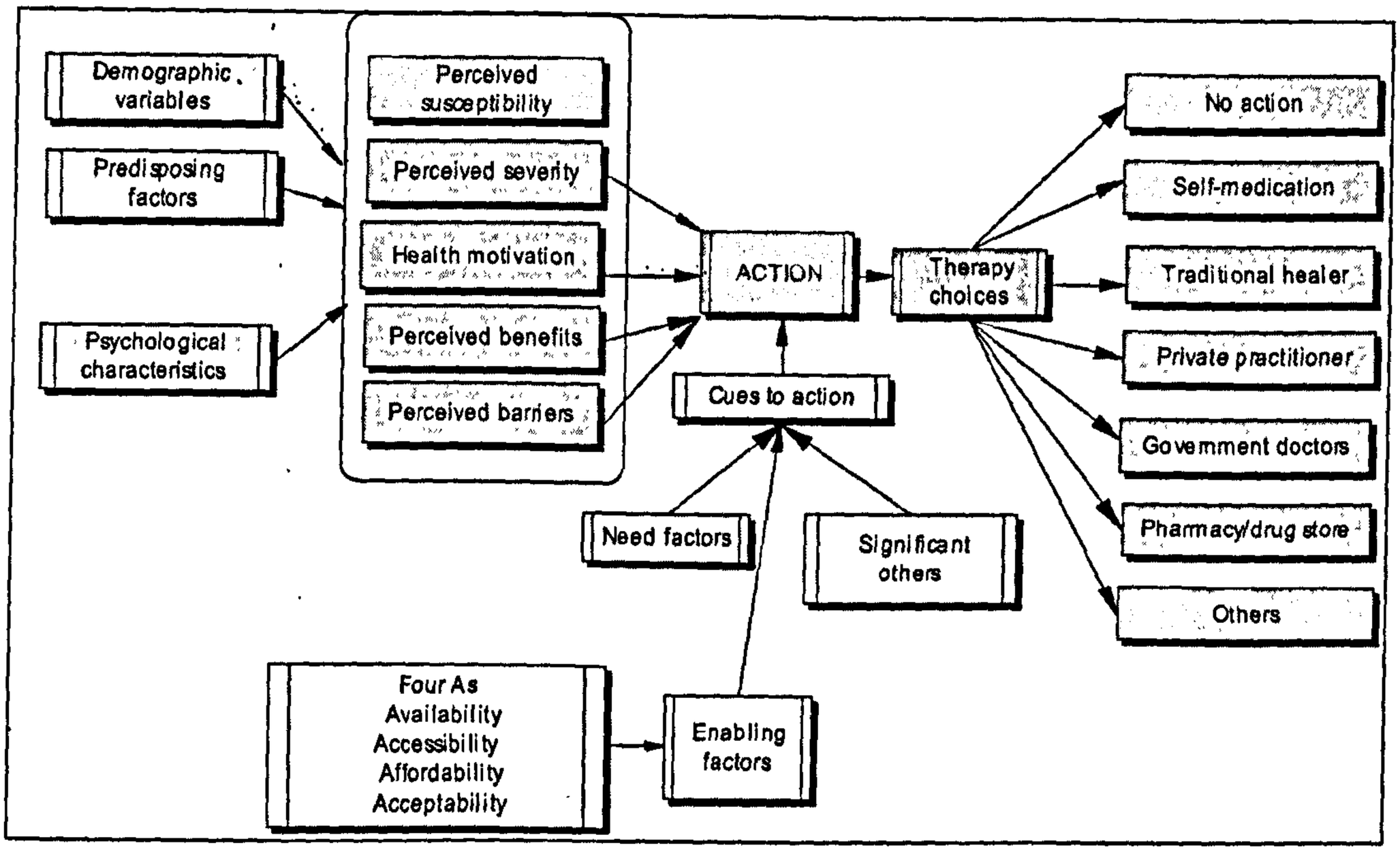
3.4 Pathway model

This model, also known as the Kroeger's model is a variant of the Andersen model (health care utilisation model)[106] and starts with the recognition of symptoms and the path that people follow until they use the different types of treatment. It acknowledges the importance of 'significant others' in the decision making process. 'Significant others' are part of the 'therapy managing group' which include relatives and friends who play the pivotal role in illness negotiations and management. This concept was elaborated by Janzen for understanding decision making in therapeutic processes. [106] The inclusion of this model in the conceptual framework was in recognising that patients draw from the general knowledge and values shared by the wider social network in decision making regarding health care use.

3.5 Hypothesis and Conceptual framework

As a result of the amalgamation of the four models, a new model is produced. (Figure 3.1) The same predictive indicators in the HBM are shown on the left side of the model which has been further expanded to the right by including elements of the other three models. This progression from patients' perceptions on severity and benefits to therapy choices helps conceptualised what is currently known between health and health care seeking behaviour and time period. The enabling factors in section 3.2 have incorporated the elements of the four As. The roles of 'significant others' need factors and enabling factors provide cues to taking action for treatment.

Figure 3.1: Conceptual framework for health and health seeking behaviour among TB patients



This conceptual framework allows for clear thinking and planning on aspects that should be included in the research. For this research, the aim is to identify among others, the explanatory factors to delay and therefore having a framework which conceptualise the patient's behaviour in relation to illness is invaluable. For example, in assessing health care utilisation, one should consider all the elements of four As. Without a conceptual framework, only one or two elements might be considered in terms of access. Furthermore, a conceptual framework also helps in identifying appropriate research methods. Some concepts can be translated into operational variables such as accessibility by using proxy measures such as distance or travelling time to the nearest health facility. These data can be collected using structured questionnaire. In contrast, concepts on the role of 'significant others' and social acceptability are better explored using in-depth interviews and focus group discussions.

3.2 Summary

The development of the conceptual framework for health and heath care seeking behaviour was based on four models: the health belief model, health care utilisation, the four As and the pathway model. They were chosen based on the fundamental aspects of the models which explained in part the patient's behaviour in seeking care and also how they explained other important factors such as access and role of other people. The conceptual framework provided conceptualised variables which need to be translated into operational variables. This will be explained in Chapter 5. It also provided insight as to the appropriate research approach for data collection.

4 CHAPTER 4: Qualitative study

This chapter documents the details of the first phase of the research which is a qualitative study to explore the health and health care seeking behaviour among the people of Sabah (Sabahans) with regards to TB.

4.1 Objectives

The specific objectives are:

a. To assess knowledge and perception of TB among TB patients and the general community through in-depth interviews.
b. To examine perceptions and experiences of health care services.
c. To examine the impact of TB on the patients and families in terms of emotional, physical, social and life practices.

4.2 Study population

The people of Sabah include 32 indigenous groups with over 80 locally spoken dialects with a wide variation in traditions and cultures. For example, the Kadazandusun, the largest ethnic group in Sabah, are predominantly wet and hill rice cultivators. Although majority belong to one of the major religions such as Christianity and Islam, some still hold to the ancient beliefs and practice. One such practice is the annual state-level Harvest Festival to honour *Bambaazon* or *Bambarayon*, the rice spirit for yet another bountiful year. The Bajaus are great horsemen and commonly known as the famous *Cowboys of the East*. The Rungus reside in the northern districts of Sabah while the Muruts inhabit the interior and south eastern parts of Sabah. This group alone has 15 languages and 21 dialects and were, until the last century, head hunters and longhouse dwellers. Most practised shifting cultivations and are skilled hunters.[39]

Even in these modern times when most Sabahans professed either Christianity or Islam, there is still a well known belief amongst indigenous people that a person may fall ill due to the works of the evil spirit or from sickness 'thrown' by someone else, a disease giver or the soul of the dead.

Ritual specialists or traditional herbalist are important persons in any village in Sabah. Their services are often sought to divine the nature of illness, to undo unfortunate events, to restore matters to original condition, to prevent sickness or to provide protection against impending harm.

The relief of sickness may be attempted in two ways: to perform ritual to divine the nature of illness and to effect its cure or the use of a variety of plants substances to treat illnesses and to provide immunity to specific diseases.[107] Consultation with traditional healers is not peculiar to the people of Sabah. It is an accepted practice in Malaysia. Among psychiatric patients in East coast of Peninsular Malaysia, 73% had consulted a *bomoh* (indigenous Malay medicine-man) prior to their visit to the government clinic.[108] Among the Semai tribe of 'Orang Asli' (indigenous people) in West Malaysia, the *Tok Halaq* (traditional healer) is the first person the community will sought advice from, even when health services are accessible.[109]

This study was conducted in 7 districts; Kota Kinabalu, Penampang, Putatan, Tuaran, Kota Marudu, Kudat and Keningau. Kota Kinabalu is the state capital with a mixture of all ethnic groups. On the other hand, Penampang is a predominantly Kadazan area where a third of the population belongs to this ethnic group and the neighbouring district of Putatan is a predominantly Malay area (57%).[110] Around 45% of the population in Tuaran are the Dusuns followed by the Bajaus (28.9%). Similarly, around half of the population in Kota Marudu are the Dusuns. In contrast, two thirds of the neighbouring districts of Kudat are Rungus while in the interior district of Keningau, two thirds are of the Kadazan-Dusun-Murut ethnic goups.[110]

4.3 Methods

The methods employed for this study were a combination of methods summarised below:

- In-depth interviews were performed on 17 TB patients from 7 districts.

- In-depth interviews were performed on 15 respondents who were either spouses, relatives or other people in the village. One of these was a village headman and two were traditional healers.
- Feedback from health staff during 2 meetings.
- Feedback from staff in charge of the TB Clinics.
- Review of past documents including newspaper cuttings.
- Observations of patients in the hospital wards.

4.3.1 Sampling methods

a. Purposive sampling

Purposive sampling to look for information-rich cases, with a mixture of extreme, typical and 'political sampling' as suggested by Patton was employed.[111] An 'extreme' case would be someone who was underprivileged and perhaps marginalised and a 'typical' case would be a self-employed person from a rural setting or an urban housewife. By using 'political sampling', someone from very deprived areas with known problem of access could be identified. The sampling matrix for the purposive sampling used in this study is as tabulated below (Table 4.1).

Table 4.1: Sampling matrix for identifying interviewee

Group	Income level and location	Gender	
		Male	Female
Patients	Low income		
	Rural	XXXX	XXXX
	Urban	XXX	XXX
	High income	X	X
Traditional healer		X	X
Family member or relatives or other key informants	Rural	XX	XX
	Urban	XX	XX
Health staff		XX	XX

Participants were identified by health staff working in the particular district based on the criteria outlined below. (

Table 4.2)

Table 4.2: Sample size, methods and criteria for eligibility

Interviewee	Methods	Criteria for eligibility
TB patients	In-depth interviews	• Smear positive TB cases and still on treatment at the time of research.
Relatives	In-depth interviews	• Has a family member or relative who is/was a TB patient. • Actively involved in the care of the patient for example the spouse, parent and children.
Traditional healers	Key informant interview	• Known to have treated TB patients
Village headman	Key informant interview	• Village headman from high risk locality.
Health staff	Discussions, feedback, observation	• From districts involved with the research.

b. Theoretical sampling

Theoretical sampling was also done because during the course of the interviews, there were interesting findings such as on stigma and effects of TB which needed to be explored. Therefore, the interviews were extended to specifically include more people who could provide such information. These findings were also supported by reviewing materials such as reports and newspaper cuttings.

c. 'Opportunistic' sampling

Information was also obtained from relatives who accompanied patients who seemed eager to be involved in the interviews. They often have more to say than the patients or were quite strong in stating their stand that patients may not want to express their views in their presence. It was helpful to bring these relatives aside and interview them separately. This was also to maintain patient confidentiality. Sometimes, an opportunity presents itself when people knew that I was conducting a research on TB. In the second phase (quantitative) of the study, some patients were more than willing to narrate their experiences and such patients were interviewed separately on these

issues. Similarly, some discussions and feedbacks from health staff at the clinic levels were often opportunistic in nature.

4.3.2 Data requirement

The data needed for the conceptual variables which were outlined in the guide for in-depth interview (Appendix 3) were:

a. Local terminology with regards to TB
b. Recognition of symptoms
c. Perception of illness
d. Health seeking and health care seeking behaviour
e. Knowledge of TB
f. Perception of care
g. Effect of disease on the patient and family
h. Community perception of TB

4.3.3 Data collection methods

a. Interviews

Interviews were carried out as agreed by the interviewees in terms of time and place. It became apparent early during the interview phase that respondents residing in urban areas prefer to be interviewed at the clinics while those in the rural areas did not mind being interviewed at home. Oftentimes, interviews conducted at home attracted the interest of more than one person. Family members seemed interested to sit in during the interviews and most respondents said that they did not have any problems with that. Only 7 respondents were interviewed in the health clinics, the rest were done at the respondents' home. After identification of respondents by the health staff of the TB Unit in the districts, verbal agreement was obtained prior to the interview. This may be through the phone or more often, a visit to the interviewees' homes. This was followed by another visit for the interview, often with the same health staff who on several occasions also acted as a translator. Translators were needed for 5 interviews. All interviews except for the first two were tape recorded with verbal permission from the participants.

b. Feedback and discussions

Most responses from the feedback and discussion sessions with health staffs were handwritten. Feedbacks from health staffs were available during two important meetings where I presented the earlier findings on knowledge of TB, perception of illness, heath seeking behaviour and also the effects of TB on their lives. The two meetings were:

i. A meeting organised by the Sabah Health Department on the 23rd November 2005 which was attended by around 25 senior public health officers.
ii. A meeting for all health inspectors and medical assistants involved in the TB Control programme throughout the state of Sabah on the 3rd December 2005. About 100 staffs were in attendance.

Many issues were also discussed with the health staff at the clinics and hospital level throughout the entire research period which was from 1st August 2005 to 30th April 2006 (9 months) especially on the reasons for patients coming late for treatment.

c. Review of relevant studies and documents

As part of data collection, I have also reviewed other documents such as anthropological studies in Sabah and newspaper cuttings to complement the findings from interviews and discussion.

d. Observations

Observations on the patients' experiences in the clinic and wards were also included in the findings.

4.3.4 Ethical issues

Informed consent was prepared and completed before the interview process. (Appendix 4)

a. Autonomy

The respondent could at any point before or during the interview refuse to proceed with the interview. In addition, he/she could indicate questions which he/she was not happy answering and the questions would be passed over. None of these occurred during the interviews.

b. Confidentiality

All information obtained was kept confidential. In instances where translators and other assistants were involved, they were also asked to keep the information confidential. The choice of translator was also important. He/she should not be recruited from the same village as that of the respondent. This again was to ensure confidentiality. Only two translators were needed throughout the research and they were not from the same village as the respondents.

c. Anonymity

This was maintained by avoiding any reference to the actual name or any other circumstances that might be easily connected to the respondents. Due to the small number of respondents, village or place of residence and even the districts were not referred to in the results. The same approach was used with health staff.

This research had the ethical approval both from the London School of Hygiene and Tropical Medicine and the Ministry of Health Malaysia. There was no external financial assistance for this phase of the research.

4.3.5 Analysis

All in-depth interviews except for the first two were taped and took between one to one a half hours to conduct. Transcription of interviews was performed immediately and in the language in which interview was conducted. Each transcription took between 4 to 6 hours. Then they were translated to Bahasa Malaysia (national language). Data analysis was done in several stages throughout the research in the national language using thematic content analysis.

a. First stage: Finding common themes

The first stage was to inform on the questionnaire which was to be used for the quantitative research. As such, general themes with regards to symptoms, causes, health care seeking behaviour and perception of care were identified.

b. Second stage: Looking for emergent categories

This was a more rigorous process of analysing the content for the emergence of new categories and subcategories. This was particularly important in identifying the various categories of effects of TB and stigma.

c. Third stage: Synthesising findings

This process involved looking for relationship between the various themes in an attempt to create a clearer understanding of TB as seen from the patients and community perspective.

d. Triangulation

Wherever possible, supporting data in various forms were added to the conceptual variables so as to present a more holistic picture. Often this included notes from short interviews, feedback and discussion. Other times, related published documents were used.

4.4 Findings

The findings presented are analysis of the interviews and where relevant, input from other sources such as from newspaper cuttings and observations are included.

4.4.1 Characteristics of participants

A total of 17 patients (P)[i] and 15 others (NP)[j] who were spouses, relatives, villagers and traditional healers were interviewed in the seven districts and

[i] In the text, the letter 'P' after the excerpt refers to that taken from the interview with patients and
[j] 'NP' to that taken from interview with non-patient participants.

they were mostly women. However, among the TB patients, seven were women and the remaining were men. The age ranges from 18 to 66 years old. Almost all participants have either no formal education or only completed primary education. Most of them were unemployed or self employed such as housewives and farmers. The ethnicity of the respondents varied; mostly were Rungus and Bajaus but there were also Kadazans, Dusuns, Muruts, Brunei, Indian and Chinese. Among the non-patient respondents, two thirds were women. The age ranged from 27 to 65 years old. Similar to the previous group, most were unemployed or self employed.

The above mentioned were those involved in the in-depth interviews. There were many others who have participated by giving short descriptions, responses and feedback who are not listed. They include 10 other patients from the quantitative study, 5 relatives and 11 health staff.

4.4.2 The community perspective of TB

"In 1960s, dwellings were sprayed for the control of Malaria. When the spray team came to a house in our village, they heard someone in the house coughing and saw a very thin and ill-looking man coughing out blood. He told the members of that household that the man might be suffering from TB. It was the first time the villagers heard of such name. Not long after that, health staff came from the state capital to treat those with TB and in those days, injections were used. They put up beds in open spaces for the patients. I noticed the adults were frightened of the injections. I was just a kid then and had never seen adults running or hiding away from the medical team. It was so funny (laughs)." (As told by a patient, NM, farmer, 55 yrs old)

The above illustrated the relatively 'unknown' TB as a disease entity in the 1960s. In most places in Sabah, 'TB' is a name introduced by the health staff to the locals in the early 1960s. Since then, TB once a nameless disease but often described by its symptoms (chronic cough, coughing out blood and being very thin) became well-known as 'TB' or '*batuk kering*' (dry cough) or '*mengurus*' (becoming thin).

In a report in the local newspaper, The North Borneo Herald of November 1883, a medical doctor in Sabah (then known as North Borneo) wrote that 'consumption' (as TB was known then) was rare[112] and indicated that TB was relatively unknown at the turn of the century. Such lack of knowledge on TB resulted in many misconceptions on the care of TB patients such as the fear of injections. In a TB prevalence study conducted among the Muruts of rural Pensiangan in 1969, many participants did not return for the Mantoux test reading because they were apprehensive about the syringes. Many thought that evil may enter the body through injections.[113] This fear of injection may also be the reason for the 'funny' incident in the narration above.

As little was known of TB, it was not regarded as 'the works of the evil spirit' and thus the role of spiritualist was minimised. Two traditional healers were interviewed and both said that they were not taught on how to treat TB. According to them such disease did not exist when they started their training at the tender age of 10 years old. One had been a traditional healer for 20 years and the other for 15 years. Instead, they believed that TB was due to hard labour and eating contaminated food and could be treated through traditional rituals such as sacrificing pigs.

Traditional medicinal plants were also used by the natives for generations in relieving symptoms of many diseases and the cure for various infections. Knowledge of medicinal plants has been the key for their survival especially among those who live in the interior. Nowadays, people who live far from towns still rely on traditional cures handed down to them through their ancestors. For example, the stem barks of *Caesalpinia sappan of* the *leguminosae* family, when boiled and drank has been used for treating TB.[114] Even the traditional healers interviewed used specific plants to try to relief the symptoms of cough. Whether this was the same plant mentioned earlier, it could not be ascertained during the interview.

Q: Have you ever treat anyone who has cough for a long time?

A: Yes.

Q: How do you treat them?

A: There is this root of a plant which he has to put in water and drink.

Q: What do you think is the cause of his cough?

A: There was some food that he has eaten.

Q: What sort of food?

A: It can be anything. It is like food poisoning.

Q: So if he drink the water with the roots, can he get better?

A: Sometimes. (NP3)

Most health beliefs surrounding the cause of TB were formulated from within the community. There is also a fusion of cause and transmission forming a hazy picture of how one gets TB. When the patients were asked as to the cause of TB, most answers revealed the way TB occurred or got transmitted. The prevailing notion is that there was a 'tear' inside the body which eventually became 'rotten' making it possible for 'something' to enter the 'tear' and caused TB. The 'tear' could have been due to several reasons; chief among these is hard work. Still, there are others who believed that TB started off as gastritis (inflammation of the stomach lining).

"According to the people here, the origin of TB, number one is gastritis. Firstly, because he did not look after his food (nutrition). You know how it is with this village people....sometime when they go to work.....they have not eaten, not taken any drinks. Hah, that is the cause." (NP5)

Some patients do not believe in this 'a tear inside the body' notion but felt that they got the disease due to work condition such as exposure to rain and sweat. Others believed that TB was caused by eating or drinking contaminated food, food that have been exposed to dirt, dust or even the saliva of TB patients. Another patient recalled the day when he had continued farming as there was still plenty of daylight but had ran out of drinking water and he

decided to drink the water seeping from the rocks. He thought maybe that was how he got TB.

There were some who agreed that TB was caused by germs but according to them, that did not explained how one got the disease. One patient thought that TB was hereditary because all his family members were affected with TB except for him and his sister. When he was told that he had TB, he was not surprised.

The traditional belief of sickness being 'thrown' by someone else proved to be more prevalent than the belief that TB was the work of the evil spirit. One patient believed that she was weakened by TB; as a result of which, it was easy for her to get 'charmed'.

A: In May, I felt this sharp pain just below my ribs. It felt painful when I cough, like being sliced by a knife. My uncle took me to see a 'bomoh' (traditional healer). *You see, last year someone cast a charm on me. I had to be treated by 4 different 'bomoh'. Before I went to see the traditional healer, I went to a private doctor and asked for a scan over the area.*
Q: When you saw the 'bomoh', did you tell him that you have TB and are still on treatment?
A: Yes, I told my family and the 'bomoh' but they told me to get treatment anyway, because I may have two illnesses.
Q: What medicine did the 'bomoh' give you?
A: Well, just water that has been 'blessed' and told me to avoid some food.
Q: Do you think that you have TB because someone has 'charmed' you?
A: No, but maybe because I am already weakened and sick by TB, then he sent another illness to me. (P1)

In another interview, an ex-TB patient related his experience of having TB some five years ago. He was getting thinner by the day and had been examined by doctors several times; had sputum examination repeatedly and also had a chest x-ray or two. However, it was apparent that he was getting

worse and thought that the end was near. His mother-in-law decided to seek an experienced healer who told him that someone has 'charmed' him. He was treated by the healer and about a week later went to the clinic again for his review. The sputum examination returned positive and a repeat x-ray revealed damage in the right side of his lungs. He believed that the 'charm' has masked his disease.

Most respondents agreed that TB is infectious and can spread through sharing eating utensils and through face to face interaction. Among some cultures in Sabah, many social gatherings involved drinking local rice wine often served in a jar and sipped through bamboo straws. Many people of this culture were of the opinion that sharing cups and eating from the same plate as well as sharing the bamboo straws were routes of TB transmission. Due to this belief, TB patients do not share utensils or meals with family members and others.

This belief that sharing bamboo straws can spread TB is quite wide spread even among local leaders. In a speech by a local assemblyman at a district level World TB Day celebration, he said *"TB is caused by a virus which can be spread through saliva. The people should be aware that among the ways that the virus can be spread in our culture is through sharing of glasses and "monsiop tapai" (rice wine sipping)."* (Reported in Daily Express (local Sabah paper), 25th June 2004.)

4.4.3 Health seeking and health care seeking behaviour

The commonest symptom was cough. This was followed by loss of weight. Continuous coughing usually affected sleep and difficulty in breathing sometimes forced patient to sleep in a semi recumbent position for relief. The other respiratory symptoms experienced were hemoptysis (coughing out blood), shortness of breath and chest pain. The most commonly feared symptoms were persistent cough and coughing out blood. The commonest constitutional symptom was loss of weight followed by fever. The other constitutional symptoms were loss of appetite, difficulty in sleeping and lethargy.

Some patients knew they had TB because they have heard of the disease or have experienced the disease in their family. Other patients thought they were suffering from other diseases but had no idea what they were. Others thought they had diseases such as diabetes, asthma, gastritis, breast cancer and common cold. One patient thought she had been 'charmed' while another two were not concerned with their symptoms and did not sought treatment until much later. Among the non-patient participants, cough and/or coughing out blood and loss of weight were identifiable with TB.

Almost all patients sought treatment due to worsening of symptoms. If cough did not get worse such as by becoming productive and persistent, this symptom would be ignored for a long time. However, if cough was accompanied with blood or difficulty in breathing or lethargy, treatment was sought promptly. One patient sought a traditional healer first before getting treating from a government clinic. This was because she and her family thought she was poisoned. Her husband told us, "*Yes.....for about a month (she took the traditional medicine). After that .....when there was no improvement, my father-in-law said....let us bring her to the hospital. First time we went, they could not find what was wrong with her, they just examined her and said that she had common cough. My father-in-law was not happy. Let us bring her back to the hospital and ask for an x-ray. That is why the second time I took her, she had an x-ray done and then we were told she has TB.*"

The first choice of treatment was related to the understanding on the cause of illness. In most instances, patients rely on modern medicine for cure. However, other options were considered when modern medicine failed to provide complete cure. More than half of the patients did subscribe to multiple forms of treatment especially when they did not find complete recovery with the treatment provided by the doctors. One patient said he bought numerous medicines before being diagnosed with TB. He began by buying some medicine through direct selling agents.

Q: This medicine, what does it do?

A: I don't know what it does. These two bottles, 5 drops from each.

Q: Is it any good?

A: I think it is quite OK. But this is what I am thinking now, this is RM40 (~USD10) each bottle, I am thinking when the doctor told me that I have scars in my lungs; I think this medicine can heal the wound but the germs don't die. They make the germs go and hide, making them more difficult to be detected.

Q: This is what you believe?

A: This is what I believe now.

Q: Did you take anything else, herbs, for instance?

A: Oh, different types of herbs, cannot be counted, whatever I hear: roots, saplings, everything, I have tried.

Q: How did you get them?

A: I look for them myself. Someone just showed me what they look like and where to get them.(P10)

This patient would not seek a traditional healer due to his religious faith, a decision which many Sabahans Christian would be able to relate to. In fact, some people may not admit that they sought traditional healers as this was considered a pagan practice.

Most patients admitted to making their own decisions regarding treatment although this is often influenced by advice from family members and relatives. Most families in Sabah are still close-knitted and in some communities such as the Rungus of Kudat, many families reside in a 'long house'.

In the past, village headmen were highly respected individuals in the community. They served under the Native Chiefs who were responsible for preserving law and order in their districts.[115] Native Law is still being practiced in Sabah and village headmen are experienced in this law. They are even allowed to perform marriages according to the natives' culture. No activities should proceed unless permitted by the village headmen. In the past, villagers even sought the opinions of the village headmen regarding illnesses and forms of treatment. However, in present days, this is no longer the case.

Upon being diagnosed with TB, patients were offered health education at the start of treatment. An examination of the health education materials at the clinics revealed that they only dealt with facts about the disease and treatment. Often, this form of providing health education may not be effective as little could be absorbed by the patients then as they reflect on how they could have contracted the disease and how their lives would be affected. At such an early stage in the treatment phase, patients may be embarrassed to discuss some sensitive issues such as whether TB was transmitted through sexual intercourse. Proper counselling sessions to TB patients has not been offered by the health provider due to lack of resources. This may attribute to poor knowledge of TB patients as revealed earlier.

In terms of patient care, most TB patients were treated on an ambulatory basis. However, one hospital routinely warded their TB patients for the first 2 months. It was distressing at first to find TB patients wandering around or idling about in the wards. Most patients said that they were bored and wished to be home. The only apparent advantage was in the physical improvement in terms of weight gain. Those warded seemed to gain weight much faster than those on ambulatory care. One patient said this was because in the hospital, they eat 6 times a day, 3 more meals than what they would have at home.

4.4.4 Impact of TB

Most patients told their family members about their disease. One did not; a bachelor who lived on his own. One patient told her relatives about the disease and another two informed other people such as church members, superior and close colleagues at the office. The reasons for not telling other people outside the family circle were mainly due to worry about other people's reaction, felt that others did not need to be told and considered TB as an embarrassing disease. One respondent was worried that people might equate TB with AIDS and distanced themselves from him.

The support that the patients received from their families in general, was good. There were various ways in which support was advanced such as

agreement to supervise medication, accompanied the patient for treatment or volunteered to get the medicine for the patient from the clinic or took over some of the patient's responsibilities such as tending the farm and cooking for the family. Family support is vital in helping the patients cope with everyday living throughout their illness period as the effects of TB on the patients' lives are substantial for example in terms of emotional and social aspects as shown below.

Despite good support from their families, some patients often felt that they were not able to discuss aspects of their disease openly. Oftentimes they were preoccupied with what others thought of them and this preoccupation affected them emotionally and psychologically. They also worry about the future; after the completion of treatment.

Judging from the depth of emotions such as worry, sadness and preoccupation, it seemed that women tend to be more affected emotionally while men tend to worry over financial and physical aspects. This is because, most male patients found it difficult to work because of the need to go to the clinic regularly for treatment and therefore became dependent on others. Sometimes, they have to borrow money from relatives and friends for bus fares. Sometimes, patients may not be able to keep their appointments as they have to earn the money for the bus fares.

"This time, it (the medication) was for 2 weeks. He gave me medicine supply for every 2 weeks. Earlier on, he asked me to come every day but I told him, I am a poor man; I do not have my own transport. Everyday I have to spend RM12 (about USD 3) for transportation, how can I bear this financial burden, I told the doctor. We discussed for quite some time and he agreed to supply the medicine for 2 weeks. I said, if for every 2 weeks, I can afford to bring my wife here (for treatment) but if every day, I said, how can I go out to sea (to fish)." (NP7)

As a result of TB, patients often felt weak and never fully recover to their pre-illness physical state. In most instances, the patients mainly the men

could not carry on with their daily work due to physical weakness. Many patients who were farmers find it difficult to continue farming due to residual weakness.

"Of course it is difficult. Before I had this disease, I was only old. But whatever I want to do, I did it on my own. But now that I have this disease, even though I am almost cured, according to the doctor and my own feelings, definitely I will not recover completely as before. So, definitely it is difficult because before this illness, whatever work, I did it myself. But now, even near the house, even when I see all the plants withered away, I cannot do anything."(P10)

Almost all the patients mentioned the need to make changes in their everyday living as a result of TB. These include separation of utensils, making new sleeping arrangement and reducing social contacts and activities. The need to separate utensils was most often initiated by the patients. Making new sleeping arrangement could cause problems between husband and wife.

"Ah, when my husband had TB, if I am not mistaken, I did not sleep with him for 7 months. He had to sleep on the floor while I slept with our second child in the bed. I think for the first 3 months he was hurt by that but I told him it is not that I am neglecting his needs but this is for our own good."(P3)

Many patients took the initiative to distance themselves from their families by keeping separate utensils, eating separately or sleeping separately. There were two extreme cases in which the patients moved out of the house temporarily during the treatment period. It was their decisions even though their family was against it. One patient rented another flat not far from his family during his treatment period. His wife came everyday to bring him food. His reason for moving out was that he was worried of infecting his baby son. Another patient moved to a small barn which also served as a store for the family's paddy stock. It was quite ironic because instead of being left on his own, his children and grandchildren and relatives never left him in peace.

Whoever brought food for him would sit and eat together with him. His grandchildren would play in the barn to keep him company. One patient was isolated by his family. He was asked to live in their farm house and looked after their farm. He sold the farm produce for money and when there was none to sell, he begged for money from friends and the public.

Besides support from their families, TB patients had little support from others. In Sabah, the only known non-governmental organisation which supports the fight against TB is the Sabah Anti-Tuberculosis Association (SABATA). It was founded some five decades ago and receives an annual grant from the government to run its activities. However, most district branches of SABATA are not active. Some respondents did receive some form of financial assistance from SABATA. However, this financial assistance differs considerably between districts. In some districts, a sum of RM15 (~USD4) was given out every month to all patients. In other districts, the patients were reimbursed for their travelling fares. At one time, some patients were given money to buy lunch while waiting for the research team to arrive. Such financial assistance, though small in sum, was important to some patients and to TB control programme as it lessened the patients' financial burden especially in terms of transportation fares. In Sabah, anti-TB drugs and hospitalisation are free. For government servants, 2-weeks medical leave is granted or longer according to the patient's medical need. Unfortunately, the same has not been offered to those working in the private sectors.

As mentioned, most patients did not tell other people outside the family circle mainly for fear of isolation or fear of negative reactions from others. This could be due to perceived stigma on the part of the patients rather than the experience of enacted stigma. In some situation, the latter may be true. One such case involved a temporary health worker who passed remarks about a couple who both had TB (P12 & P13). The couple operates a small grocery stall in the village.

Wife: We don't take our medicine from the clinic here. (Laughs)

Q: So, where do you get your medicine?

She mentioned another clinic, about 20 km from the village.

Q: Why?

Wife: We are embarrassed, because a lot of people have been talking, they said we are infectious. We had a tiff with some of them. We did not ask for this disease, we told them.

Q: Who did you quarrel with?

Wife: With the health worker. He told the villagers, don't go and buy from their stall.

Husband: Don't play with their children. Don't go near them or you will get infected. He called us the "TB grocer".

Q: He is working at the clinic here?

Husband: Yes but now he has stopped working there.

Q: So it was just him or the other staff as well?

Wife: Just him.

Husband: He is the only one but he told many people.

Q: What about the other villagers?

Wife: They are OK.

Husband: They treat us the same as before.

Q: Did anyone come to buy things from your stall?

Wife: Not at the beginning. (Laughs)

Q: How long did that last?

Wife: Maybe 3 days.

Husband: Not 3 days, more like a month.

Q: Why is that?

Wife: Well, they were scared.

Husband: They were scared until I told them, although we are sick like this, we have never brought our plates and beg for food from you. I maybe sick but I can feed myself, I told them. They said we are 'TB grocer' and that hurts. If someone had said that I have TB, I am not ashamed, I did not ask for this. And I am not the only one with TB here.

In the above mentioned case, perhaps there was more than enacted stigma on the part of the health staff. He may have resented the couple as they were not originally from the village and also of a different race. In general, there is a great tolerance for multi-ethnic existence within a village in Sabah. However, the above incident suggested that hostility may not be attributed solely for having TB. It also revealed how easily the villagers could be 'frightened' into keeping their distance and just as easily, changed their reactions when one appealed to them sensibly.

Stigma was also assessed from the community's perspectives represented by views from non-patient respondents. It was disturbing to find that in some communities, TB patients who are single faced a poor prospect of marriage.

A: For example, when he comes to our house, so as usual, during meal time, we feed him too. After that, we separate his bowl and plate. When he has left, we wash his bowl and plate, first with soap water then with hot water. That is what we have been told.

Q: In your opinion, if someone has TB, can he get married?

A: If according to our custom, he can't, because he is like, physically deformed. After all he cannot look for job. It means that he can no longer be responsible for his family. (NP14)

It also appeared that stigma did not disappear after cure. One elderly patient when asked how she could have contracted the disease narrated a family gathering which was attended by a relative who was known to have TB. Although that relative had completed treatment, she was not sure whether he was cured and seemed to be under the impression that she could have got the disease from him. This could be due to inadequate knowledge on the curability of TB or an underlying belief that a TB patient would always remained one. This might explain the reason why some people do not want to marry someone who had TB. It seemed that stigma (perceived and enacted) might be deeply rooted within all the communities. However, there are some

evidence that stigma has lessened over the years as shown as observed by a patient.

"This disease, it is like a disgrace. Last time (in 1987), when my husband was sick, so we went to the hospital, when they know that my husband has TB, they were afraid to come near my husband. This, from hospital staff, from nurses. Maybe now, this disease is like normal, not like before, too embarrassing to tell others."(P3)

It is difficult to hide one's disease from the other villagers. In our experience, it seemed that once a person gets TB, almost everyone in the village would know. The extent to which one would hide his/her disease reflected the stigmatising effect of TB. Most patients especially in urban areas and those who did not have financial difficulties preferred to be interviewed in the clinic. However, one lady who lived in a rural village would rather walk for 2 hours to her brother's village to be interviewed rather than have us visit her at her village.

4.4.7 Patient and health care provider views of TB care

The patients' and relatives' perception of care provided by government and private clinics was generally fair; most respondents said that the care was good or that they did not encounter any problems during their consultations with doctors. However, two did not wish to comment and another two were frustrated with the doctors who could not diagnose their disease early.

Many health staff did not realised the impact TB has on the patients' lives as there were very little discussion regarding these effects between health staff and the patients. Also surprising was on the lack of knowledge on TB among the patients and community despite several decades of efforts in health education on TB. It is likely that in the past, the emphasis was more on case identification and completion of treatment. Little was done in understanding the socio-cultural dimensions of the disease. Health education materials were factual and standardised without addressing some of the misconceptions

surrounding TB. A senior officer related how a phone call to a patient's office from the Health Department resulted in the patient's fury as she did not want anyone in the office finding out that she has TB. Another staff related how health staffs were sent off when they made a home visit in full uniform and using the department vehicle. This sort of behaviour poses difficulty for the team as they have to conduct case investigations which involve visiting close contacts. In this study, since it was hard to predict the participants' reaction to being interviewed, the choice of place for interview was left entirely to the participants.

The summary of this study was also presented to health personnel in two meetings as already mentioned. It was felt that the study highlighted misconceptions and stigma surrounding TB that should be communicated to the health providers which cannot wait until the completion of the research. Based on the responses during the two meetings, it was clear that the patients' and community's perspectives were quite different from that of the health providers'. Most health staff did not realised that the patients' and community's knowledge were poor and that the effects were considerable.

Most health staff expressed these opinions as to why patients present late;

- Patients live far from health facilities and public transportation is scarce.
- They face financial difficulties especially for transportation as most patients are poor.
- Patients think that their illness is not serious and that they may recover through their own effort such as buying medicine from medicine shops.
- For mothers, they may find difficulty in leaving their small children.
- Farming activities made patients postponed an intended visit to seek treatment as there was nobody to tend to their farm in their absence.
- Not able to get away from work; among estate workers or those on daily wages, taking the day off to go to the clinic may mean no income for the day.

While the reasons given are valid and reflected in some of the answers provided by the patients and community, the clearer understanding among the health staff of the health and health care seeking behaviour of the community is lacking. There was no mention that patients might be embarrassed about the potentiality of being diagnosed as TB or that negative attitudes of health staff may deter patients to seek treatment early.

4.5 Discussion

From this study, greater understanding of the patients' and community's perspectives was made possible and will be discussed here. To my best knowledge, this is the first documented perspectives of patients and communities regarding TB in Sabah.

4.5.1 Health culture in relation to TB

Most health beliefs surrounding the cause of TB were formulated from within the community. In terms of the cause of TB, the germ theory is not well known. Most respondents associated TB with something that they have done such as hard work, eating contaminated food or exposure to extreme conditions. Some patients still believe that they were 'charmed' and thus vulnerable to TB. There is a parallel in the belief that hard work causes TB between the Sabahans and other communities such as the Vietnamese[88], Mexican[3, 90], Achenese[92] and Filippino[84].

Most respondents believed that TB is infectious regardless of the cause. This is in contrast to the belief among Vietnamese where if TB was due to hard work (Lao luc), it is considered not contagious.[88] Some people still believed that TB was hereditary while most believed that it is spread through means in which droplets or saliva or breathing space was shared.

Secondly, most patients did not attribute their symptoms to TB. This is not surprising as the symptoms are not specific to TB and can wax and wane. This finding is not different from the study done in West Malaysia in which only 1.5% of the respondents attributed their symptoms to TB.[94] As TB was not

due to the works of evil spirit, the natural course of action was to seek modern medicine. Even the few patients who sought traditional healer later sought modern medicine when they did not get better, perhaps after re-interpreting their symptoms.

One of the reasons for the inadequate knowledge on TB in the community is due to the unavailability of information and insufficient publicity surrounding TB. Majority of the participants obtained information from other people and only a handful mentioned getting information from health staff or health education materials distributed by the Health Department. Information on TB in the media was sketchy and infrequent. A review on a local newspaper, Daily Express which is widely distributed and published in 3 languages (English, Malay and Kadazan language) revealed only 6 articles on TB between 2003 and 2006.

However, the wide distribution of this newspaper may still be ineffective in disseminating facts on TB as illiteracy in Sabah is still high; in 2000, 21% of the population of 6 years and above have never attended schools and this ranges from 7% among the Chinese to 21% among the Bajaus.[116] The use of other sources of information such as television and radio might be just as ineffective. Electricity coverage for households especially in rural Sabah was reported to be 65% prior to 2004.[117] Even in health facilities, education materials on TB were hard to come by. For those who seek information through the internet, information on TB on the website of local medical and health departments or Anti-TB organisations is basic and not adapted to address local interpretation. It is therefore not surprising that the community continued to formulate their own understanding as to the cause and mode of transmission of TB.

Since TB was not suspected by most patients, being diagnosed as having TB created more negative feelings. However, my suspicion is that the degree of negativity might be compounded by underlying fear of isolation and discrimination. This is suggestive of deep rooted stigma towards TB patients,

the nature of which were expressed through certain acts such as using separate utensils and reducing social contacts. Studies in other countries also strike similar patterns such as the use of separate utensils among TB patients in Amazon Peruvian community[118], Zambia[18], Kenya[93] and Thailand[56]. Subsequently, this could have contributed to the psycho-social effects on TB patients which resulted in low self-esteem and withdrawal from society thus creating a vicious cycle.

Family support during the treatment process of TB patients is needed. At least two patients who live with their families but did not involve them in the treatment process have defaulted treatment. There was a patient who was warded for almost 2 months before our interview which was considered a long period. This was because none of his family members were able to supervise his medication-taking. Prior to hospitalisation, he lived on his own. After missing his daily treatment several times, he was warded. He has four children, all with their own families. His son said that he was busy with his work and he could not take care of his father or supervise his treatment. Many a morning, the nurses would find him in his own clothing claiming that his son would take him home that day. Eventually the son would turn up in the afternoon only to say that he would not be taking him home that day. This experience was traumatic for him and also the staff.

There was also suggestion that discrimination of TB patients persisted even after cure. This seemed to contradict the admission by most respondents on their belief in the curability of TB. Discrimination could persist because TB patients sometimes do not recover to their pre-illness physical state thus considered as permanently weakened or deformed. For single patients, TB may affect their prospect of marriage; similar to findings in Pakistan[119] and Gambia[18]. The persistent of stigma after completion of treatment noted in this study was also described among South Indian patients.[120]

It is not clear from this study the extent to which health staff contribute to the perpetuation of stigma although during observation in the clinic, one

health staff was overheard advising a patient to use separate utensil. Whether such advice was given by other health staff is uncertain. In a study in Pakistan, stigma was perpetuated by health staff who recommended 'voluntary social isolation', to cover their mouth when coughing and to use separate eating utensils.[119] In Kenya, stigma was perpetuated by the health staff by isolating TB patients and the use of special measures such as doormats being impregnated with chemical and the use of gloves before entering TB ward.[93]

Female TB patients did not suffer increased enacted stigma compare to men. This could be due to the complementary role women play in family and social functions among most ethnic groups in Sabah. In Northern Thailand, female TB patients were not stigmatised any more than men due to women's hold to the inheritance of authority.[56]

4.5.2 Strengths and limitations of the study

This study contributed considerably to aspects of TB particularly on the health culture and health seeking behaviour among TB patients and the community where previously there was so little documentation. The strength lies in it being first hand information of patients' own experiences and from other members of the community. In addition, it covered the opinions expressed by different ethnic groups in seven districts and from all walks of life.

Wherever secondary data was available, they were added to build a more complete construct. Although the findings could not be generalised to the whole population of Sabah, it added several more pieces of understanding to the current understanding of TB. It also exposed potentials for future research such as in the measurement of stigma using psychometric testing and intervention studies on improving awareness and knowledge on TB.

As mentioned above, one of the limitations of the study is that the findings are confined to only several ethnic groups mainly the Kadazandusun, Bajau

and Rungus. It is possible that other ethnic groups have different health seeking behaviour for TB.

Assessing the internal validity of the findings is difficult as the truth is often subjective. There is also some bias when the interviewer is connected to the Health Department. Perhaps patients may not reveal their true health seeking behaviour for various reasons despite the assurance of confidentiality and anonymity. However, the use of triangulation methods such as getting information from spouses and relatives and sometimes through published materials helped in improving the validity of the findings. The findings were also considered reliable as all interviews used a topic guideline and where feedbacks and discussions were concerned, the similar guideline was used throughout.

4.5.3 Contribution to the questionnaire development

The qualitative study was instrumental in the development of questionnaire for the quantitative phase. Earlier contributions to the formation of the questionnaire were from WHO (personal communication with Dr. Jane Cunningham, WHO Geneva), work done by Paul Pronyk (personal communication with James Hargreaves, lecturer, LSHTM) and the questionnaire used by MOH Malaysia for the TB prevalence survey. A draft of the questionnaire was already available prior to the start of the research. The qualitative study helped the development of questionnaire in the following areas.

a. Terminology

Attempts were made to ensure that certain terminologies were understood by the community. It was found that "TB" was a known and accepted name of the disease.

b. Explore the ways to get a date for the onset of symptoms.

It was obvious from this study that getting the dates for the onset of symptoms would prove difficult. The participants as with the majority of

population did not have a keen sense of time. The strategy was to identify certain occasions commonly known to the public such as festivals and public holidays. In addition, the dates should be asked in a systematic manner; beginning with year, followed by the month and then the day.

c. Exploration of the possible range of answers

This study allowed for the exploration of the possible range of answers especially on causes and symptoms of TB among others.

d. Identify sensitive areas

All patients in the qualitative study were more than willing to relate their illness in terms of symptoms. It was a good way to start the interview. Views on what they thought were the causes of their illness and their perceptions needed to be approach in an understanding manner as most patients wanted to appear rational in their thinking. For example, some respondents may be wary about saying that TB was caused by evil spirits as that may seem 'ridiculous' to health staff. Similarly, the lowered tone and the change in the expression such as sadness and hurt suggested how TB has affected their lives. Personal behaviour of smoking, consuming alcohol or substance abuse was asked at the end of the interview, in a 'by the way' manner. Often, the patients were comfortable after relating their illness that it was easy to probe the sensitive questions after that.

4.5.4 Recommendations

Although WHO has provided very generic means in reducing TB incidence such as increasing case detection and ensuring high cure rate, the lack of understanding on the community perspectives, cultural practices and attitudes towards TB may be a reason why TB remains a threat.

Based on this study, there is a need to discuss some of the misconceptions and the lack of knowledge on TB. Patients need to recognise the symptoms of TB early so that treatment can start early. A reinforcement of the message "cough of two weeks or more - think TB unless proven otherwise" need to be conveyed to the community. In addition, the curability of the disease must

remain as one of the key points; aptly summarised in the words of a patient, "I would rather have TB than HIV because TB is curable and HIV is not." Finally, the whole concept should be 'sold' as a package since fragmentary information will allow the public to create their own understanding to replace the missing pieces. This information package needs to be channelled through various means to cater for the different needs of the population. More support from various groups needs to be garnered for those affected by TB; the patients and their families. By taking such action, TB will be brought out into the open so that the stigma surrounding it will soon fade.

Future research can explore health and health care seeking behaviours among other ethnic groups and also among immigrant population. In addition, in-depth analysis of stigma and TB would assist in reducing its effect on health seeking behaviour and on the lives of TB patients.

4.6 Summary

The objective of the study was to understand the socio-cultural dimensions of TB in the Sabah context using qualitative approaches such as interviews, observations and discussions. Although information from individual participants was fragmentary, by using triangulation methods, a broader picture of disease recognition, perception of illness, knowledge on TB and health seeking behaviour in relation to TB in Sabah has emerged.

Knowledge on TB was generally unsatisfactory. Most participants did not know the cause of TB and some misconceptions such as TB being hereditary still prevail. Most patients did not perceive the symptoms they had as that of TB. However, the prevailing practice among the respondents was to seek modern medicine for cure. Other forms of treatment such as traditional medicine were also sought if modern medicine failed to provide cure.

TB is still a stigmatising disease and the expression of this was in both perceived and enacted ways. TB also affects the patients in various aspects of their lives such as psycho-social, physical, financial and life practice. The

findings from this study served as eye-openers for most health staff. The extent to which these socio-cultural factors affect the time lapse in the process of care among TB patients are the objectives of the next phase of the research.

5 CHAPTER 5: Methodology for quantitative study

The quantitative study is a progression from the qualitative study and builds on earlier understanding on health and health care seeking behaviour for possible TB in the Sabah context. This chapter presents the objectives and methodology used.

5.1 Aims and objectives

The aims of the study is to describe the various time periods in the management of TB and identify explanatory factors for patient and doctor delay using pre-determined cut-off points.

5.1.1 Specific objectives

a. To document the time period from onset of symptoms to start of TB treatment amongst smear positive PTB cases. This includes the patient, non-government practitioner, doctor and total time period.
b. To identify explanatory factors for patient delay, defined as > 30 days, from onset of symptoms to presentation at any health provider.
c. To identify explanatory factors for doctor delay, defined as > 14 days from seeking treatment from a doctor to start of treatment.

5.1.2 Secondary objectives

a. To identify explanatory factors for patient delay of > 90 days.
b. To identify explanatory factors for doctor delay of > 60 days.

5.2 Outcome measures

a. Patient delay (in days) from onset of symptoms to first consultation (first presentation with a health care provider which include pharmacy and traditional healers) is defined as > 30 days as a primary outcome and then greater than 90 days as secondary outcome.

b. Doctor delay (in days) from consultation to a doctor (government or private) to start of treatment is defined as >14 days as a primary outcome and then greater than 60 days as secondary outcome.

5.2.1 Definition of a patient with TB

The definition of a new smear positive TB patient for this research adopted that used for the National TB Information System (TBIS), Ministry of Health, Malaysia.[121] A new TB case is:

a. One who had just been diagnosed as having TB and has not received any anti-TB treatment prior to the diagnosis OR
b. A TB patient who had been put on anti-TB drugs within the past 4 weeks OR
c. One who claimed to have been treated with anti-TB drugs but had no record of being registered as a TB patient.

A smear positive TB patient is:

a. one who had at least 2 smear positive slides OR
b. had 1 smear positive slide AND chest x-ray suggestive of PTB OR
c. had 1 smear positive slide AND sputum culture positive of *Mycobacterium TB*

5.2.2 Inclusion and exclusion criteria

The inclusion criteria were:

- Newly diagnosed smear positive TB patients
- 18 years of age or older
- Malaysians
- Registered with TB at one of the 10 districts (see section 5.5.1 for further description)

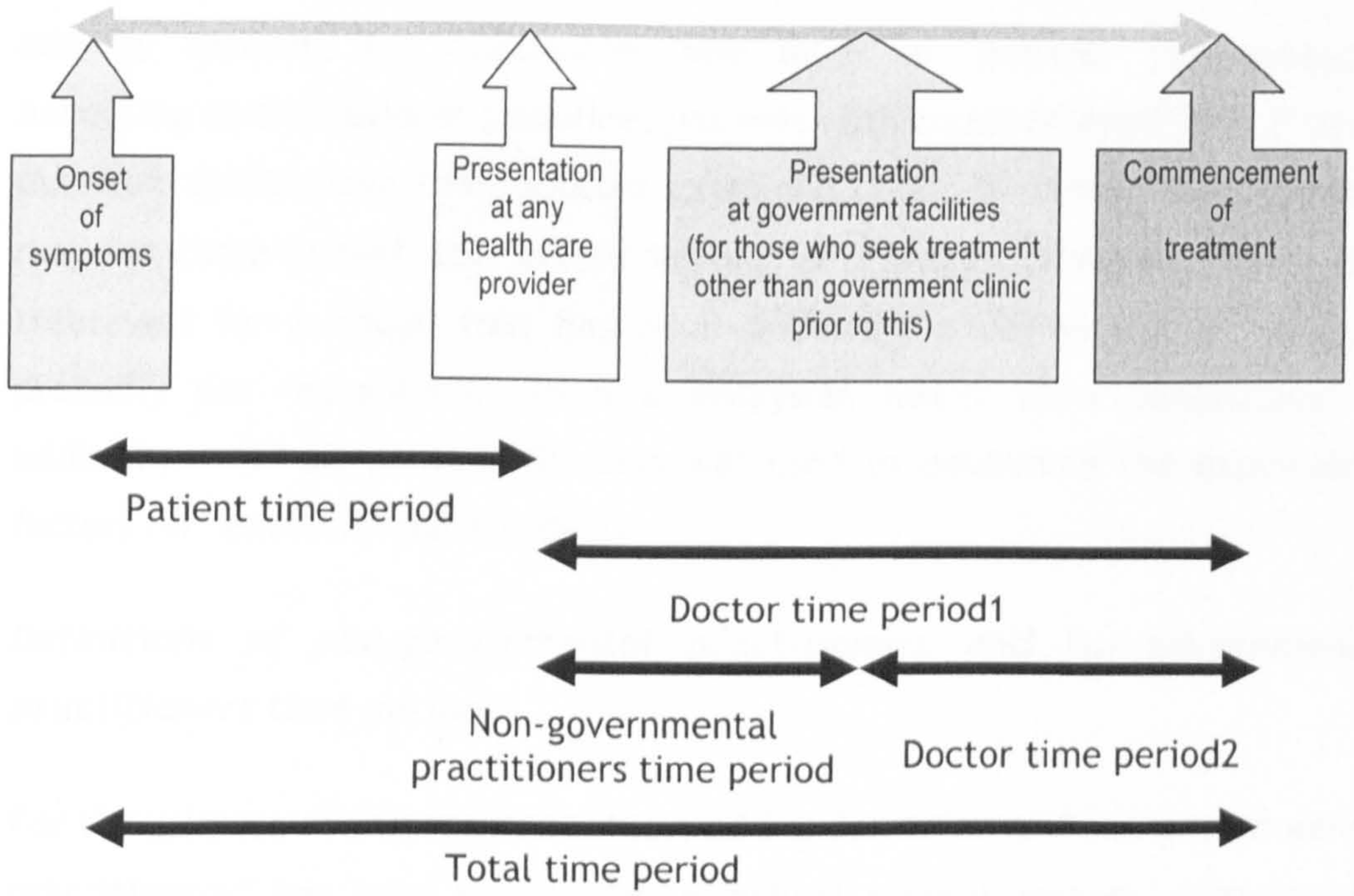
The exclusion criteria were:

- Those too ill to participate. However, those hospitalised for whatever reason but were able to be interviewed were included.
- Patients identified through contact investigation. This was because the period from onset of symptoms to first consultation was not relevant. However, contacts of patients that eventually become patients themselves and sought treatment on their own were included. Although, one can argue that having a TB patient in the family or within a community can alter health seeking behaviour through raised awareness, it may not always follow that awareness and knowledge get translated into action.
- Non Malaysians were excluded due to their mobility. From my own experience, they are fairly mobile as most are in the country for job opportunities and often came illegally and thus maybe suspicious of any study done by government agencies. This issue was difficult to deal with within such a tight research schedule and so was outside the scope of this study, important though it is.

5.3.3 Definitions of time period and delay

For the purpose of the research, time period in the management of TB is divided into a number of intervals as shown in Figure 5.1.

Figure 5.1: Time period milestone in the management of TB



Definitions of total time period

This period is defined from the onset of symptoms to the initiation of treatment. This is made up of patient time period and doctor time period (doctor time period1 or non-governmental practitioners time period and doctor time period2) as shown in Figure 5.1.

Definitions of patient time period and patient delay

The patient time period is defined as the interval between patient's onset of signs and symptoms suggestive of TB (restricted to cough, fever, loss of weight and blood stained sputum) to the first presentation at any health care providers. Any health care provider is defined as medical practitioners (both government and private), pharmacists or traditional herbalist or healer.

A cut-off point of 30 days was used to dichotomise the respondents into 2 groups. Those with a patient time period of 30 days or less were considered to

have 'no patient delay'. This acceptable delay is based on the Malaysian guideline (Practice Guideline for the Control and Management of TB, 2002) and by catering for reasonable time lapse in 'normal' circumstances. According to the national guideline, patients with cough of more than 2 weeks duration should have their sputum examined.[122] In some cases, patients may not come immediately after coughing for 2 weeks. However, not to seek treatment for a cough that has been bothering a patient for 1 month is probably not 'acceptable' from a Malaysian health care perspective. In addition, a cut-off point of 90 days was used to determine the explanatory factors for 'extreme' patient delay.

Definitions of non-governmental practitioners and non-governmental practitioners time period

For the purpose of this research, the working definition of "non-governmental practitioners" has been broadened to include private doctors, pharmacists, medicine shop owners and traditional practitioners. This is because in Malaysia, traditional practitioners and other form of therapy are being registered and regulated. The Traditional and Complementary Medicine Unit in the Ministry of Health was set up some years back to coordinate and implement various activities on traditional and complementary medicine in relation to practice, training and policy.

The non-governmental practitioner time period is defined as the interval between presentation to any non-governmental practitioner and to consultation at a government clinic.

Definitions of doctor time period and doctor delay

The period between the presentations to any doctors (either government or private clinics) and the commencement of treatment defines the doctor time period and is illustrated in Figure 5.1 by doctor time period1 and doctor time period2. For those whose first visit to a health care provider was at government or private clinic, the period is doctor time period1. For those whose first visit to a health care provider was not at a government or private

clinic, this period refers to when they are eventually seen by a government doctor and is illustrated as doctor time period2.

For participants who first attended a health care provider other than a doctor, a government doctor was the next health care provider visited for all except for one patient. This patient saw a private doctor who referred him and was seen by a government doctor on the same day. Therefore, in this case, the period is still doctor time period1.

A cut-off point of 14 days was used to dichotomise the respondents into 2 groups. Those with a doctor time period of 14 days or less were considered to have 'no doctor delay'. An acceptable period for both diagnostic and treatment time period is one week for each. One week is more than enough to determine whether a patient has TB in a straight forward case. According to the national guideline, at least 3 sputum samples are needed: spot, morning and spot specimen are collected over a period of 2 days. In the absence of chest x-ray, 2 positive smears can be justified for starting treatment. Patients are started on treatment by medical officers almost immediately after diagnosis. However possible delay in starting treatment may occur if there is no medical officer in the health facility (often manned by medical assistants) which is common in Sabah. This 'delay' has been taken into account in the construction of acceptable delay from consultation to start of treatment. Similar to patient delay, a cut-off point of 60 days was used to determine the explanatory factors for 'extreme' doctor delay.

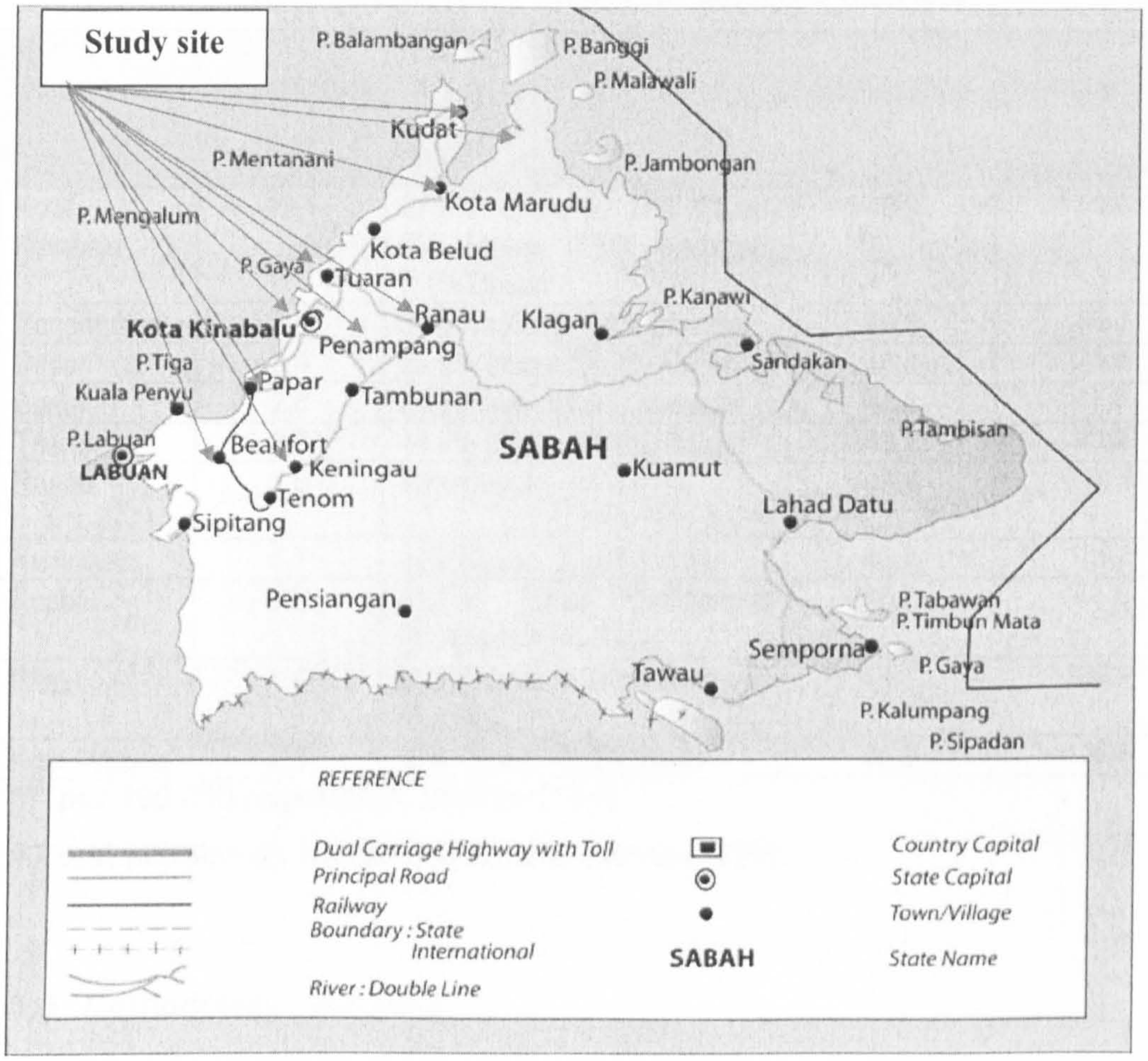
5.4 Study population

The population under study is the same as that described in section 5.2. Ten districts in Sabah were selected for phase 2 of the research based on the following criteria:

a. Logistics

As shown on in Map 2, all the districts are accessible from the state capital, Kota Kinabalu where the research team was based.

Map 2: Study sites in Sabah



Source:[123]

b. Smear positive TB notification rate

All the districts have considerably high notification rates ranging from 50 to 135 cases per 100 000 population. (Table 5.1)

c. Balance in ethnicity and sex

Most of the ethnic groups in Sabah were represented by the 10 districts with almost equal number of men and women in each district. (Table 5.1)

Table 5.1: Population composition (1998) and smear positive TB notification rates (2000) for selected districts

District	% of total population#	Ethnic group#	% female of population#	Smear positive TB notification rate (2000)**
Kota Kinabalu	12.1	27.6% Chinese, 11% Bajau, 9% Malay, 7.5% Kadazan, 7.4% Dusun	48.9	50.0
Penampang	5.0	30% Kadazan, 16% Chinese	48.6	55.0
Papar	3.4	25.2% Malay, 24.5% Kadazan	48.8	73.9
Beaufort	2.8	21% Malay, 12.9% Kadazan	48.6	77.8
Tuaran	3.7	44.7% Dusun, 28.9% Bajau	49.2	83.9
Ranau	2.8	80% Dusun	48.1	135.9
Keningau	5.1	40% Dusun, 13.7% Murut	46.8	126.2
Kudat	3.2	61.7% Other indigenous (Rungus), 8.7% Bajau	48.3	82.1
Pitas	1.4	68.7% Other indigenous group (Rungus)	48.2	132.9
Kota Marudu	2.5	53% Dusun, 12.5% Bajau	48.3	110.5

** per 100 000 population. Source:[124]

Total population (1998): 1,734,685. Source: [125]

5.5 Methodology: Sampling

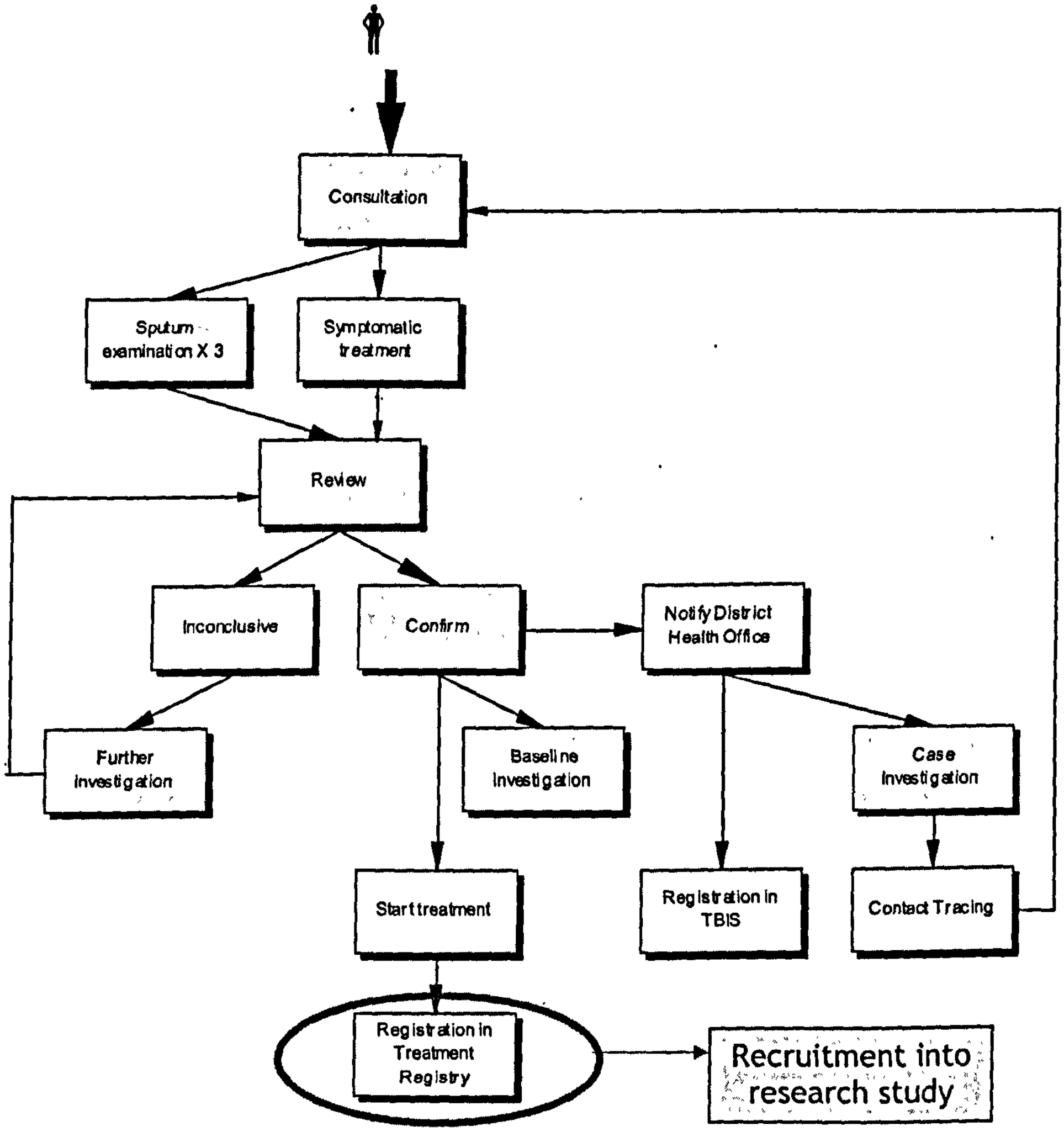
5.5.1 Sampling and recruitment process

In all the districts, the flow chart for the management of TB patient is as illustrated diagrammatically in Figure 5.2. A patient with cough who presented to the health facility could either be treated symptomatically or subjected to sputum examination. This depends on various factors including the general health of the patient and also the duration of cough. For patients with cough of 2 or more weeks in duration, sputum specimen for examination should be requested as stated in the Practice Guideline for the Control and Management of TB (2002).[122] At least 3 specimens would be needed and sometimes more if the quality of specimens provided were unsatisfactory. The criteria for a diagnosis of smear positive pulmonary TB has been outlined in 5.2.1.

Once a patient is diagnosed as having TB, a standardised regime of treatment commenced. As required by the law the case should be notified by the attending doctor to the nearest health office for registration in the District Registry (TBIS). (Figure 5.2) This Registry is maintained by Health Inspectors. At the same time, the patient is also registered in the Treatment Registry which is kept at the treatment centre and maintained by the Medical Assistant-in-charge of the treatment centre. It was from this Treatment Registry that respondents for the research were identified.

The Treatment Registry is kept at health centres where diagnosis and treatment are available. They are known as PR1 (treatment centre 1) while the rest, usually smaller health centres and community clinics are known as PR2. PR1 are often bigger health centres with medical officer, laboratory support and sometimes with x-ray facilities. In a district, there may be more than one PR1. PR2 serves as treatment centres only and these are health facilities with no medical officer but may have diagnostic facilities. If patients sought treatment at PR2, they would have to be referred to PR1 and may be referred back to PR2 to continue treatment if they wished.

Figure 5.2: Flow chart for the management of TB patients in a government health facility



Participants were recruited into the study based on their entry into the TB Treatment Registry in the 10 districts involved. Prior to the start of the study, all staff in the TB Control Units from the 10 districts attended a meeting in which they were briefed on the inclusion criteria, how to identify potential respondents and on the procedure for arranging interviews. In the districts of Kota Kinabalu and Penampang, I identified the respondents. In the other

districts, either the Medical Assistants-in-charge of the TB Clinics or the Health Inspectors-in-charge of the TB Unit would assist in the recruitment to save travelling time. This was done by identifying eligible respondents based on the inclusion criteria and then asked the respondents whether they were willing to participate in the study. Verbal consent was obtained at this stage and a list of eligible respondents was prepared. I would then reconfirm the recruitment when the team visited the district for the interviews to ensure that the inclusion criteria have been adhered to. I also went through the TB Treatment Registry again to ensure that all eligible patients have been identified. The visits were often as weekly for neighbouring districts of Kota Kinabalu but never more than three weeks for the other districts. Before interview, an explanation of the study and the content of the consent form would be read to the respondents and interview would only proceed after written consent was obtained.

5.5.2 Sample size calculation

The calculation for the sample size for this study was based on the Penang study in 1994. In that study, being male, having below secondary education level, drug users and those who have seek private practitioners prior to government doctors tend to have longer patient delay.[58] The situation in Sabah is somewhat different in term of the availability of private clinics. Private clinics are mainly found in city or town centres and scarce in rural areas. In that study, the odds ratio for those with lower education was 3.3 for delay longer than 30 days where the percentage with delay (defined as > 30 days) in the 'unexposed' (high education level) is approximately 20%. However, bearing in mind that more than half of the population in Sabah reside in rural areas, the expected percentage of delay among the same education group was expected to be higher than 20%.

For this research, a sample size based on a type I error of 5%, 80% power and an odds ratio of 2.0. The ratio between the unexposed and exposed was also explored in terms of 1:1, 1:2 and 2:1 as shown in Table 5.2. Assuming that the percentage with delay in the unexposed group was 30%, an OR of 2.0 and a

ratio of unexposed to exposed of 1:2, the total sample size was 347. Allowance of a 10% refusal rate, including missing values and other factors, the estimated size for this study was 386. The calculation for sample size was carried out using Epi Info 6.04d.

Table 5.2: Estimation of sample size

Ratio of unexposed to exposed	% in unexposed	% in exposed	OR	Sample size (not taking into account 10% refusal rate)		
				unexposed	exposed	Total
1:1	20	33.3	2.0	186	186	372
	25	40	2.0	165	165	330
	30	46.2	2.0	153	153	306
1:2	20	33.3	2.0	142	284	426
	25	40	2.0	125	250	375
	30	46.2	2.0	116	231	347
2:1	20	33.3	2.0	274	137	411
	25	40	2.0	244	122	366
	30	46.2	2.0	226	113	339

5.5.3 Field preparation

Prior to the commencement of the research, the following activities took place (Table 5.3).

Table 5.3: Field preparation for the quantitative study

Activity	Participants	Purpose	Duration
Meeting	• State TB team • Area Medical Officer of Health • Coordinator of District TB team	Briefing on the purpose of the research and on the research protocol	1 day
Meeting and training	• Health Inspectors • Medical Assistants	Briefing on the purpose of the research and on the research protocol	1 day
Training	• Research assistants (RA)	Interview technique Questionnaire Data entry	3 days

I was responsible for gaining access to the health facilities and the community involved, recruitment and training of research assistants, recruitment of participants, arrangement of work and travelling schedules and analysis of data. Three research assistants (RAs) were employed for this study. Their

education was at the diploma level. They were responsible for conducting interviews, completing questionnaires and data entry. Their training involved interview techniques and to gain familiarity with the details on the questionnaire such as the techniques for asking specific questions, prompts and also local terminologies of certain aspects. The RAs also practised doing interviews with each other and then observed when I did a participant interview before performing interviews on their own. I sat in almost all the interviews and was with them all the time as the team travelled together. I was therefore able to supervise them throughout the study period. At the end of each day, all completed questionnaires were checked to ensure the completeness and also aided in the learning process for the RAs.

5.5.3 Contact procedure

An attempt at first contact with respondent took place almost immediately upon confirmed eligibility based on the inclusion criteria. The health staff that provided treatment to the patient were asked to inform the patient that a research study was going on and asked the patient whether he/she was willing to be interviewed. If the patient agreed, the health staff would inform the research team. An appointment date would be set which was communicated to the patients by the health staff. In the event that a patient was not interested in the study (refused), this was noted together with the reason for declining.

Before the interview, the patient's eligibility in terms of the inclusion criteria would be verified again. During the interview, the patient information sheet and consent form was read to the patient. Some respondents were wary about putting down their signature but agreed to give verbal consent. In these few instances, the consent form was filled by the RA and another witness, often the health staff, would testify to the verbal consent.

Every attempt was made to contact the patients who did not turn up for their appointment. Due to the movement of the team between 10 districts, often it was not possible to reschedule the appointment to the next day. However,

such cases were given priority and every attempt was made to interview them within the next 14 days. In cases where attempts to contact a patient did not result in an achieved contact, the individual was defined as non contactable. However, this status was only accorded after a minimum of 3 attempts. This was done to minimise selection bias.

The details of interviews in terms of district, dates and numbers interviewed are tabulated in Appendix 6.

5.6 Data collection and entry

5.6.1 Data description

The descriptions of data that were collected are listed below.

Table 5.4: Data descriptions

Conceptual variables	Level of determinants	Operational variables
Socio-demographic	Distal	Sex, age, race, education level, income, ownership (house, transport, land, livestock, TV, radio), marital status, geographic location,
Symptoms	Proximal (doctor delay)	Cough, chest pain, shortness of breath, hemoptysis, loss of weight, loss of appetite, fever, lethargy, insomnia
Medical and family history	Intermediate	Problem with mobility, co-morbidity, family history of TB,
Social history	Distal	Smoking, alcohol consumption and substance abuse
Knowledge	Not shown in analysis	Ever heard of TB, cause of TB, Is TB infectious?, Is TB curable?
Heath care utilisation	Intermediate	Ever use health facility, number of times used over past year, travelling time, mode of transportation, usual first place for treatment
Heath care utilisation	Proximal (patient delay) but intermediate (doctor delay)	Current choice for treatment
Examination	Proximal (doctor delay)	Sputum at first visit, repeat visit, referral, number of days for chest x-ray, number of days for sending sputum, hospitalisation

Conceptual variables	Level of determinants	Operational variables
Effect of disease	Not shown in analysis	Physical, emotional, financial, social and change in life practice
Stigma	Not shown in analysis	TB is embarrassing, isolation, not tell others of disease or treatment, work prospects and lifelong effect

5.6.2 Pilot study

A pilot study was conducted in Kota Kinabalu to test the questionnaire for the following: length of time taken for completion of interview, ambiguous questions, and clarity of instruction, to eliminate questions that did not yield desired information.

Twenty TB patients (both smear positive and negative) who were already on treatment were chosen from several PR1 (health clinics where diagnostic and treatment facilities are available). Minor alterations were made to the questionnaire as a result of this pilot study. The final version of the questionnaire used was in Bahasa Malaysia and an English version is inserted in Appendix 7.

5.6.3 Interviews and data abstraction

The structured questionnaire was administered in face to face interviews by the RAs. An interview took 45 minutes to an hour to conduct, longer if translation into local dialects was required. A maximum of 4 interviews a day for each RA was manageable.

Participants were identified by a unique study number. All data collected from the patients (questionnaires) were stored in a locked cupboard when not in use. Computers used for the study were password protected with limited access. In addition to data collected from interviews, abstraction of laboratory results was also conducted from patients' case notes. A copy of the abstraction form in shown in Appendix 5. These include results of sputum microscopy, chest x-ray and date of starting treatment.

5.7 Data processing and analysis

5.7.1 Data management

At the completion of the interview, manual checking of the information obtained was performed by the interviewers. This was repeated at the end of the day by the research team. Incomplete answers were treated as missing data. The information was then coded and double-entered into Microsoft Access database by the RAs. Comparison of the double data entry and data cleaning was also performed before analysis. Data analysis was performed using the statistical package STATA version 9.1.

5.7.2 Descriptive analysis of variables

Categorical data were summarised using frequency tables. Continuous data were grouped into 3-5 levels. For example, age was grouped into 5 groups of 10 years interval except for the first and fifth groups. Regrouping of ethnic groups was also made; other indigenous races beside Kadazan-Dusun-Murut and Bajau were grouped together and other non-Sabahans as one group. Data were illustrated using frequency tables or bar charts.

Variables were also cross-tabulated to explore association between explanatory variables for e.g. sex and education. Hypothesis tests for associations between the explanatory variables were done using the chi-square test. Comparison of median was done using the Wilcoxon rank-sum test when normality of the data could not be assumed.

5.7.3 Calculation of time period

Four dates were needed to calculate the various time periods in this study; date of onset of symptoms, date of first presentation at any health care provider, date of presentation at a government health facility (for those who did not consulted a doctor as the first health provider) and date of starting treatment. There were difficulties in determining the date of onset and this is described in more detail in this section.

Patient time period was calculated as the interval between the onset of symptoms and the date of first presentation at any health care provider. Both dates for onset of symptom and seeking treatment were asked during the interview.

The respondents were first asked whether they remember the exact date of onset or seeking treatment (see questions 31 in Appendix 7). If they could not recall the exact date, they were asked in stages beginning with the year, then the month and followed by the day of the month. If they could not recall the exact day, they were asked whether it was in the beginning, middle or end of the month.

When data for the year or month unavailable, no date could be generated and so coded as missing. In situations where the year and month were available but the day of the month was recorded as either 'early', 'middle' or 'end', recoding was done; 'early' was coded as the 5^{th}, 'middle' as the 15^{th} and 'end' as the 25^{th} of the month. Where the day was reported as 'cannot remember', it was coded as the 15^{th}.

In addition, during the interview, the duration (in days) of each of the nine symptoms (in days) experienced was also obtained and respondents were also asked how long they waited after realising the symptoms before seeking treatment.

To calculate the patient time period, the date of onset of symptoms and date of first presentation with any health care provider are required. However, due to missing values for the date of symptoms onset (32 respondents), the decision was to use the maximum duration of four symptoms (cough, hemoptysis, fever and loss of weight) to generate the date of onset.

Data on maximum duration of symptoms was available for 275 respondents. For 21 respondents, the maximum duration of symptoms was not available. For 11 of these respondents, the period between when the patient first

realised the symptoms to the time of seeking treatment was used. Using these periods, 286 dates of onset of symptoms could be generated.

Data on time period were summarised and presented by showing the median and inter-quartile range (IQR). The Kaplan-Meier plot was used to show time from onset of symptoms to first contact with a health provider for patient delay and from first contact with a doctor to the start of treatment for doctor delay.

5.7.4 Outcome measurement

Time periods were recoded into binary outcomes defining no delay and delay, using a pre-determined cut-off point. For the primary outcomes, cut-off points of 30 days and 14 days for patient and doctor delay respectively, were chosen. A secondary analysis, investigating factors associated with 'extreme' delay, used the cut-off points of 90 days and 60 days for patient and doctor delay respectively.

5.7.5 Univariate analysis

Univariate analyses were conducted to assess the association between explanatory variables with the outcome (delay). Odds ratios and 95% confidence interval (CIs) were calculated using logistic regression. Hypothesis testing was carried out using the likelihood ratio test (LRT). For ordered categorical variables such as age group, tests for linear trend and departures from linearity were performed using the LRT.

5.7.6 Multivariate analysis

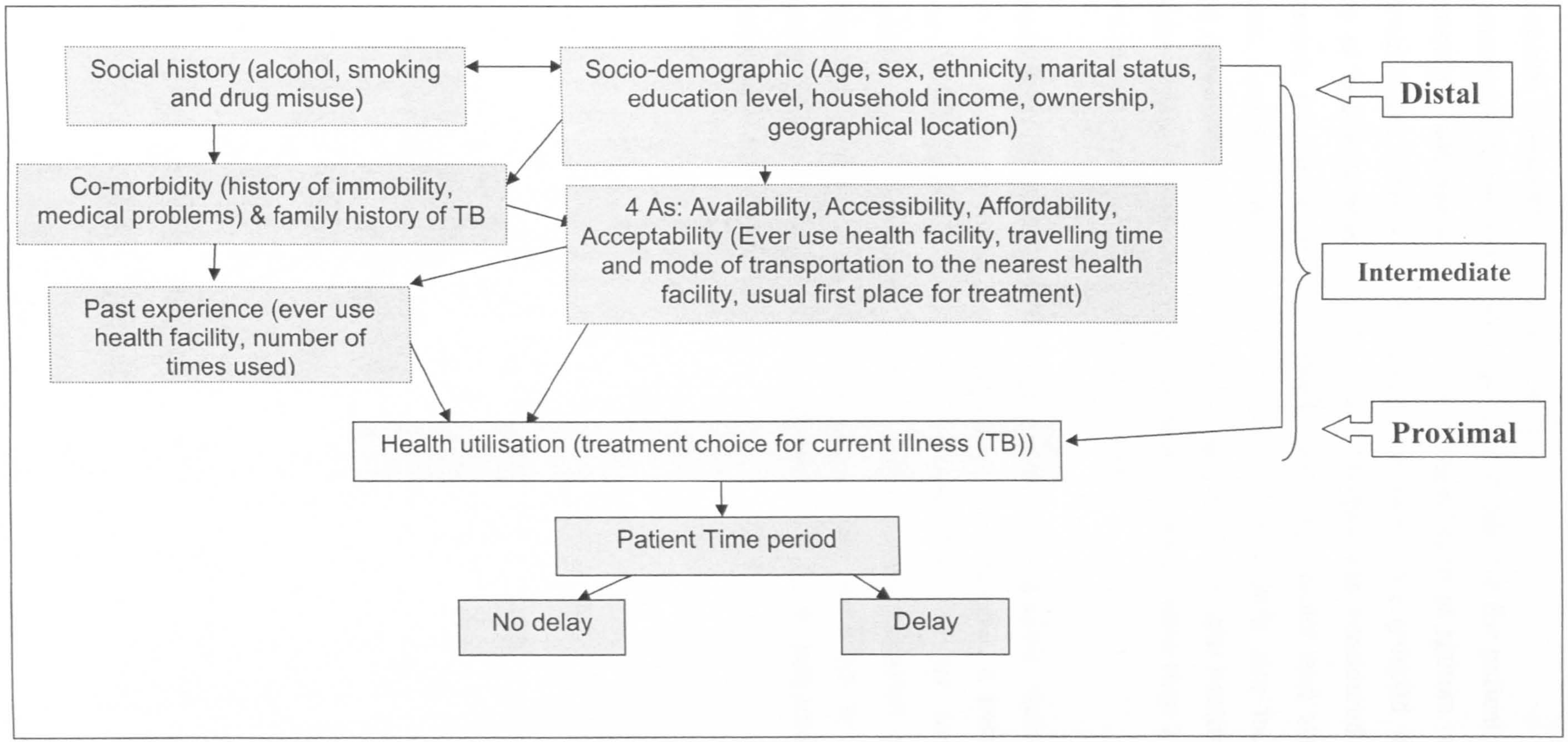
Conceptual frameworks (Figure 5.3 and Figure 5.4) were formulated for both patient and doctor delay prior to analysis. They were the simplified version of the conceptual framework in 3.5 for use during the analysis phase.

a. Conceptual framework for patient delay

This conceptual framework is based on previous studies and the current knowledge on risk factors for TB. There are three levels to the framework; distal, intermediate and proximal level.

The direct measure of time period is in relation to the choice of treatment by the patients or in other words, the health care utilisation. This category forms the proximal determinant. Health care utilisation in turn is a reflection on the understanding of the illness based on many factors and the mental process of where, how, when, what and from whom treatment should be sought. Socio-demographic factors influence health and health seeking behaviour directly; several studies have highlighted the differences between genders with regards to health and health care seeking behaviour. These factors are in the distal level. However, they also have an indirect influence through intermediate determinants such as the elements of the four As. For example, income and education may decide accessibility and affordability. The presence of co-morbidity indirectly affects health and health care seeking behaviour as part of the 'past experience' phenomena. Co-morbidity is related to socio-demographic and social factors; certain disease has predilection for certain sex, age or ethnic groups. Diagrammatically, the levels are shown in Figure 5.3.

Figure 5.3: Conceptual framework for multivariate analysis for patient delay

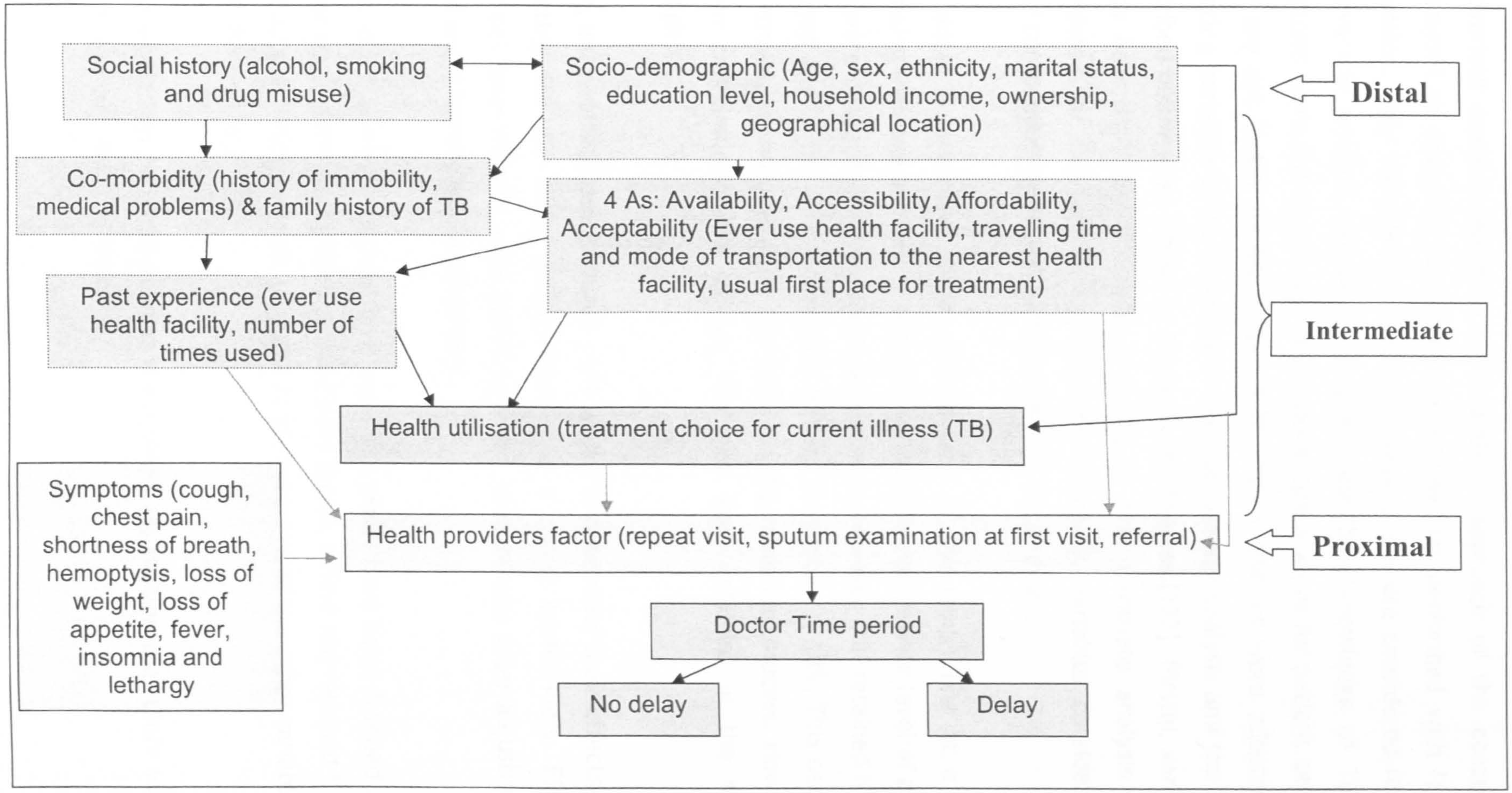


b. Conceptual framework for doctor delay

This framework (Figure 5.4) is an extension of the one for patient delay. In this framework, additional variables are included such as sputum request at first consultation, referral, and repeat visit which are grouped under the category of health provider factors. This category was considered proximal determinants for the time from consultation with doctor and starting TB treatment. Symptoms experienced by the patients were also included as proximal determinants as they influence the decision by the health provider to consider a diagnosis of TB. A patient with cough of more than 2 weeks is supposed to be subjected to sputum examination.

Past experience, the four As and some socio-demographic factors affect 'uptake' of health service recommendations. For example, a positive past experience encourages a patient to comply with request for further examination. Again, based on previous studies, low education level and increasing age tend to increase doctor delay. This could act by affecting directly the uptake of health service recommendations or indirectly through the intermediate determinants.

Figure 5.4: Conceptual framework for multivariate analysis for doctor delay



Multivariate analysis based on a hierarchical approach of the conceptual framework as described by Victora et al[126] was performed with logistic regression. Only variables in the hierarchical model are considered for the multivariate analysis. As such, variables describing knowledge of TB and symptoms were not included in the multivariate analysis for patient delay as they are not in the model (Figure 6.3). Two strategies were adopted for selecting variables to be included in the multivariate analysis and the steps described below were similar to the steps by Thomas.[127] Firstly, variables which have significance levels of $p \leq 0.2$ in the univariate analysis were considered for the multivariate analysis. Secondly, variables considered *a priori* confounders were also included such as sex and age.

The distal determinants were entered first in the model one at a time beginning with age and sex. If they did not reach a significance level of $p \leq 0.1$, they were dropped. Potential confounders were however still retained if they changed any of the effect estimates (OR) of interest by $\geq$ 10%. This decision was consistent throughout all the stages in the modelling process. However, known confounders such as age and sex were retained in the model throughout.

Then, intermediate determinants were added to determine their effects after adjusting for the distal determinants and *a priori* confounders. Finally, proximal determinants were added to assess their effects after adjusting for distal and intermediate determinants.

Those distal and intermediate level variables which have been dropped at an earlier stage were added back to the model one at a time and retained if they reached a significance level of $p \leq 0.1$ in the presence of the other variables or if OR changed by $\geq$ 10%.

The analysis was performed under the *a priori* assumption that there was no interaction between the variables.

5.8 Resources and time frame

This research received financial support through the submission of a successful grant application to the Ministry of Health (MOH), Malaysia during the second year of the DrPH programme. The grants were under the MOH Allocation for Research Development and awarded yearly. The grant allowed payment for the salary and traveling allowances for the 3 research assistants. The field work was conducted from 1st November 2005 to 30th April 2006.

6 Chapter 6: Descriptive analysis of cross sectional study

This chapter presents the descriptive analysis of the quantitative study. The recruitment process is described and the age and sex distribution of respondents and non respondents is compared. The study sample is summarised, TB symptoms experienced by respondents are described and the total time period summarised.

6.1 Numbers identified in the recruitment centres

As mentioned in section 5.5, PR1 are health facilities which serve as diagnostic and treatment centres where the Treatment Registry is kept and from which potentially eligible respondents were initially identified. In every district, there is at least one PR1 but in districts with relatively dense population such as Kota Kinabalu, Penampang and Tuaran, there are more than one (Table 6.1).

Table 6.1: Number of respondents and recruitment centre

District & PR1 Chest Clinic (CC)	No. of patient registered from 1st Oct,2005 to 31st March, 2006	No. of smear positive patients	No. of patients eligible for interview	No. of patients who died before interview, refused or not contactable	No. interviewed (actual number interviewed for the district)
Kota Kinabalu					
· CC Luyang	169	92	48	9	39
· CC Inanam	44	33	20	7	13
· CC Menggatal	53	36	23	4	19
· CC QE Hospital	115	43	28	15	13 (84)
Penampang					
· CC Penampang	45	28	22	3	19
· CC Putatan	31	22	5	2	3 (20)
Papar					
· CC Papar	39	34	28	1	27 (27)
Beaufort					
· CC Beaufort	43	35	23	4	19 (17)
Tuaran					
· CC Tuaran	63	42	38	6	32
· CC Tamparuli	6	5	4	1	3 (35)
Ranau					
· CC Ranau	45	23	18	3	15 (15)
Keningau					
· CC Keningau	79	56	36	5	31
· CC Sook	26	20	13	6	7 (37)
Kudat					
· CC Kudat	57	49	32	6	26 (25)
Pitas					
· CC Pitas	25	18	12	2	10 (9)
Kota Marudu					
· CC Kota Marudu	59	48	32	4	28 (27)
Total	899**	584	382	78	304 (296)

** The numbers include duplicates.

In some instances, duplicates were found during the verification of eligibility and confirmed by the national identification card number. These were patients who may have sought treatment at another health facility, diagnosed and started on treatment there but after some time, chose to continue treatment at a different clinic nearer his/her home. Patients who were transferred from other districts which were not included in the study were not processed for interviews. Whereas, patients from the districts included in the

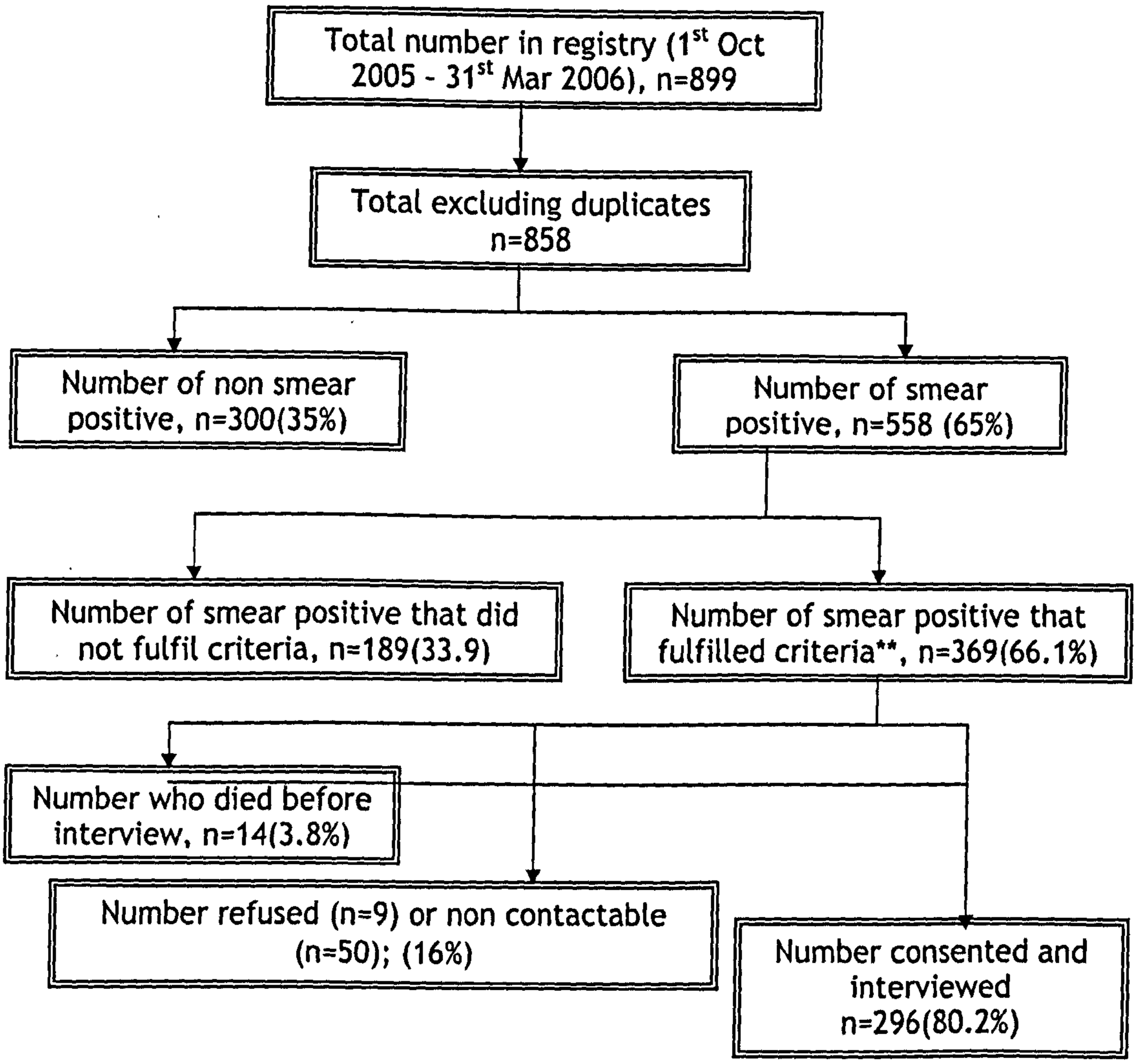
study but who had transferred to another district which was not included were traced for interview (2 respondents).

Of the 858 patients registered between 1st October 2005 and 31st March 2006, 65% were smear positive. Of these, 66% fulfilled the inclusion criteria. (Figure 6.1) For those who did not fulfil the criteria, the reasons were non Malaysians (108), less than 18 years old (30), detected through active case finding (4), restarted treatment or relapse (24) and extra-pulmonary cases (8). Ten respondents were from districts not included in the study while 7 started treatment before the 1st October 2005 but only registered after that date.

6.2 Response percentage

A total of 296 (80.2%) respondents were available and consented for interview. (Figure 6.1) The response percentage across districts ranged from 70.6% for Kota Kinabalu to 96.4% for the district of Papar.

Figure 6.1: Flow chart for identifying eligible respondents



**Eligibility criteria: Newly diagnosed smear positive PTB, 18 years and above and Malaysians

A comparison between the non-respondents (death, refused or non contactable; n=64) and respondents in terms of age and sex revealed little difference except for those in age group of 50 though overall data were compatible with no association of age and responding.(Table 6.2)

Table 6.2: Comparison between respondents and non-respondents in terms of sex and age group

Variable	Respondents n=296		Non-respondents n=73		p-value (X^2)
	No	% (col)	No	% (col)	
Male	189	63.9	48	65.8	0.25
Female	107	36.1	25	34.2	
18 - 29 yrs	87	29.4	23	31.9	0.86
30 - 39 yrs	57	19.2	14	19.4	
40 - 49 yrs	59	19.9	13	18.0	
50 - 59 yrs	41	13.8	5	6.9	
≥ 60 yrs	52	17.6	17	23.6	

6.3 Time lapse from start of treatment to interview date

In most PR1 centres, registration of patients into the Treatment Registry was often made on the same or following day. However, in some PR1 centres, it was longer especially, when there was only one staff manning the Registry. Interviews were attempted as soon as patients were registered in the Treatment Registry though sometimes, there was some delay due to logistics reasons.

The median duration between date of commencement of treatment and date of interview was 37 days (IQR: 18 - 67, range 0 - 185 days). There was no difference in interview duration between the male and female (for male: median: 37 days, IQR: 17 - 68 days; for female: median: 37 days, IQR: 19 - 65 days, p-value=0.89). One fifth (20.3%) of the respondents were interviewed within 2 weeks of starting treatment and almost two fifths within 30 days. Almost a third (31.1%) was interviewed 60 days or more after starting treatment.

The highest percentage of those interviewed 60 days or more after the start of treatment was in the district of Pitas (Table 6.3). This town of Pitas is about 210 km from the state capital, Kota Kinabalu and involved a 3-hour drive from the state capital. It is relatively underdeveloped compared to other districts in terms of infrastructure. A total of 8 visits were made over the period of 6 months. The town of Beaufort is just over 100 km from the

state capital and took about 1-2 hours driving time. Most patients opted to be interviewed at the clinic.

Table 6.3: Time lapse from start of treatment to interview date (≥ 60 days) by district

Variable	Total number interviewed	Frequency (row%) with time lapse ≥ 60 days
Kota Kinabalu	84	24 (28.6)
Penampang	20	6 (30)
Papar	27	7 (25.9)
Beaufort	17	9 (52.9)
Tuaran	35	8 (22.9)
Ranau	15	5 (33.3)
Keningau	37	10 (27)
Kudat	25	8 (32)
Pitas	9	7 (77.8)
Kota Marudu	27	8 (29.6)
Total	296	92 (31.1)

Patients were given the option for place of interview. Overall, approximately 75% opted for interviews at the TB clinic, health office or health centre. The other places for interview were hospital wards (11.8%) and patients' homes (13.5%).

6.4 Descriptive analysis

This section describes the study population in terms of socio-demographic, medical, family and social history and the health care utilisation pattern in terms of frequency and distribution between men and women.

6.4.1 Characteristics of study population

Table 6.4 summarises socio-demographic, medical, family and social history and health care utilisation of the 296 respondents. Of the 10 districts involved in the study, almost a third (28.4%) of the respondents resided in Kota Kinabalu which is the state capital followed by Keningau (12.5%) from the largest town in the interior division of Sabah.

Table 6.4: Description of respondents

Variable	Frequency (col %)	Male (col %)	Female (col %)	p-value (X^2)
Socio-demographic factors				
Location[k]				
Urban	63 (21.3)	35 (18.5)	28 (26.2)	
Rural	233 (78.7)	154 (81.5)	79 (73.8)	0.12
Sex				
Male	189 (63.8)			
Female	107 (36.2)			
Age group (years)				
18 - 29	87 (29.4)	50 (26.4)	37 (34.6)	
30 - 39	57 (19.3)	38 (20.1)	19 (17.7)	
40 - 49	59 (19.9)	40 (21.2)	19 (17.8)	
50 - 59	41 (13.8)	26 (13.8)	15 (14)	
≥ 60	52 (17.6)	35 (18.5)	17 (15.9)	0.66
Ethnic group				
Kadazan-Dusun-Murut (KDM)	141 (47.6)	90 (47.6)	51 (47.6)	
Bajau	56 (18.9)	36 (19.1)	20 (18.7)	
Other Sabahans	75 (25.3)	47 (24.9)	28 (26.2)	
Chinese	15 (5.1)	12 (6.3)	3 (2.8)	
Other Malaysians	9 (3.0)	4 (2.1)	4 (4.7)	0.52
Education				
None	61 (20.6)	25 (13.2)	36 (33.6)	
Primary	104 (35.1)	71 (37.6)	33 (30.9)	
Secondary	106 (35.8)	79 (41.8)	27 (25.2)	
Form 6 and above	24 (8.1)	13 (6.9)	11 (10.3)	
#Unknown	1 (0.3)	1 (0.5)	0	<0.001
Marital status				
Single	68 (23.0)	52 (27.5)	16 (14.9)	
Married	201 67.9)	127(67.2)	74 (69.2)	
Others (separated, divorced, widowed)	27 (9.1)	10 (5.3)	17 (15.9)	0.001
Respondent income**				
No fixed income	148 (50)	68 (36)	80 (74.8)	
< USD 132	63 (21.3)	50 (26.5)	13 (12.1)	
USD 132 - USD263	53 (17.9)	45 (23.8)	8 (7.5)	
USD 264 - USD 789	30 (10.1)	24 (12.7)	6 (5.6)	
> USD 789	1 (0.3)	1 (0.5)	0	
#Refused	1 (0.3)	1 (0.5)	0	<0.001
Household income**				
No fixed income	18 (6.1)	11 (5.8)	7 (6.5)	
< USD 132	83 (28)	47 (24.9)	36 (33.6)	
USD 132 - 263	89 (30.1)	59 (31.2)	30 (28)	
USD 264 - 789	84 (28.4)	55 (29.1)	29 (27.1)	
> USD 789	13 (4.4)	9 (4.8)	4 (3.7)	
#Don't know	8 (2.7)	7 (3.7)	1 (0.9)	
#Refused	1 (0.34)	1 (0.5)	0	0.68

[k] The definitions of urban and rural were based on the availability of services provided by the city or town council such as garbage collection rather than the usual population density. This is because there is no record of localities (villages or housing areas) that are designated as urban or rural based on population density.

Variable	Frequency (col %)	Male (col %)	Female (col %)	p-value (X^2)
Owner ship[##]				
Own house	189 (63.8)	123 (65.1)	66(61.7)	0.56
Own transport	101 (34.1)	70 (37)	31 (29)	0.16
Own land (n_{miss}=1)	153 (51.7)	99 (52.7)	54 (50.5)	0.72
Livestock	104 (35.1)	71 (37.6)	33 (30.8)	0.24
TV	230 (77.7)	155 (82)	75 (70.1)	0.02
Radio (n_{miss}=5)	213 (72)	145 (77.5)	68 (64.8)	0.02
Type of housing@				
'Village' house	236 (79.7)	159 (84.1)	77 (72)	
Residential area	26 (8.8)	12 (6.4)	14 (13.1)	
Squatters	4 (1.3)	3 (1.6)	1 (0.9)	
Quarters	10 (3.4)	4 (2.1)	6 (5.6)	
Long house	3 (1)	3 (1.6)	0	
Others	17 (5.7)	8 (4.2)	9 (8.4)	0.04
Medical, family and social history				
Problem with mobility				
No	258 (87.2)	170 (89.9)	88 (82.2)	
Yes	38 (12.8)	19 (10.1)	19 (17.8)	0.06
Co-morbidity (n_{miss}=2)				
No	203 (69.1)	136 (72.3)	67 (63.2)	
Yes [++]	91 (30.9)	52 (27.7)	39 (36.8)	0.10
Asthma	21 (23.1)	15 (28.8)	6 (15.4)	
Diabetes mellitus	16 (17.6)	9 (17.3)	7 (17.9)	
Hypertension	32 (35.2)	17 (32.7)	15 (38.5)	
Heart problem	8 (8.8)	5 (13.5)	3 (7.7)	
Family history of TB (n_{miss}=1)				
No	140 (47.5)	99 (52.7)	41 (38.3)	
Yes	155 (52.5)	89 (47.3)	66 (61.7)	0.02
Alcohol intake (n_{miss}=1)				
Never	105 (35.6)	41 (21.8)	64 (59.8)	
Past intake (ex)	153 (51.9)	117 (62.2)	36 (33.6)	
Current	37 (12.5)	30 (16)	7 (6.5)	<0.001
History of smoking (n_{miss}=1)				
Never	123 (41.7)	40 (21.3)	83 (77.6)	
Ex-smoker	130 (44.1)	108 (57.4)	22 (20.6)	
Current	42 (14.2)	40 (21.3)	2 (1.9)	<0.001
History of drug misuse (n_{miss}=1)				
No	276 (93.6)	169 (89.9)	107 (100)	
Yes	19 (6.4)	19 (10.1)	0	<0.001*
Health care utilisation				
Ever use government facility				
No	47 (15.9)	38 (20.1)	9 (8.4)	
Yes	249 (84.1)	151 (79.9)	98 (91.6)	0.01
Number of times used in the past year (n_{miss}=4)				
Never	47 (16.1)	38 (20.4)	9 (8.5)	
None	51 (17.5)	35 (18.8)	16 (15.1)	

Variable	Frequency (col %)	Male (col %)	Female (col %)	p-value (X^2)
1 - 2 times	67 (22.9)	43 (23.1)	24 (22.6)	
More than 3 times	127 (43.5)	70 (37.6)	57 (53.8)	0.01
Usual first place for treatment				
Government clinic	215 (72.9)	130 (69.1)	85 (79.4)	
Private clinic	52 (17.6)	35 (18.6)	17 (15.9)	
Pharmacy	15 (5.1)	11 (5.9)	4 (3.7)	
Others	13 (4.4)	12 (6.4)	1 (0.9)	0.09
Mode of transportation:				
To the nearest clinic				
Public transport	136 (45.9)	85 (45)	51 (47.7)	
Own transport	105 (35.5)	75 (39.7)	30 (28)	
Walk	55 (18.6)	29 (15.3)	26 (24.3)	0.06
To the nearest hospital				
Public transport	183 (61.8)	117 (61.9)	66 (61.7)	
Own transport	106 (35.8)	67 (35.5)	39 (36.4)	
Walk	7 (2.4)	5 (2.6)	2 (1.9)	0.91
To the treatment choice for current illness (TB)				
Public transport	149 (50.3)	93 (49.2)	56 (52.3)	
Own transport	117 (39.5)	79 (41.8)	38 (35.5)	
Walk	30 (10.2)	17 (9)	13 (12.2)	0.48
Travelling time:				
To the nearest clinic				
Less than 15 min	153 (52)	103 (55.1)	50 (46.7)	
15 - 29 min	99 (33.7)	61 (32.6)	38 (35.5)	
≥ 30 min	42 (14.3)	23 (12.3)	19 (17.8)	0.29
To the nearest hospital				
Less than 15 min	51 (17.3)	30 (16)	21 (19.8)	
15 - 29 min	111 (37.8)	76 (40.4)	35 (33)	
≥ 30 min	132 (44.9)	82 (43.6)	50 (47.2)	0.42
To the treatment choice for current illness (TB)				
Less than 15 min	105 (35.6)	72 (38.1)	33 (31.1)	
15 - 29 min	105 (35.6)	65 (34.4)	40 (37.7)	
≥ 30 min	85 (28.8)	52 (27.5)	33 (31.1)	0.48
Treatment choice for current illness (TB)				
Government clinic	216 (73)	132 (69.8)	84 (78.5)	
Private clinic	73 (24.7)	52 (27.5)	21 (19.6)	
Pharmacy	5 (1.6)	4 (2.1)	1 (0.9)	
Others	2 (0.7)	1 (0.5)	1 (0.9)	0.37

** 1 USD - Ringgit Malaysia 3.80

Not included in X^2 test.

Ownership of each asset is not mutually exclusive.

@ Regrouped for X^2 test; squatters, quarters, long house and others combined into one group.

++ The denominator for main co-morbidity (medical conditions) was the total number with medical conditions.

[+] Fisher's exact test

The youngest respondent was 18 years and the oldest was 88 years old with 64% were men. Almost 80% were rural residents as the whole of Sabah is more rural than urban. Almost half of the respondents were of the Kadazan-Dusun-Murut ethnic group, the predominant ethnic group in Sabah. One third of the respondents had primary education and another third with secondary education. In term of respondents' income, half of the respondents did not have any fixed income but for household income, only 6% did not have fixed income. However, almost all households have some form of assets even those with no fixed income.

Most respondents lived in 'village' houses which are often individual dwellings with surrounding land area and built from wood, bricks or bamboo as in the rural areas. Less than 10% of the respondents lived in residential areas and the rest lived in 'provided dwellings' such as government quarters or estate housing, squatter areas and long houses. A long house is a building on stilts which houses as many as 30 families in partitioned rooms. The respondents were also asked on the number of rooms used as bedrooms in their homes. The number of bedrooms or 'sleeping area' ranged from 1 to 12 while the number of occupants (adults and children) ranged from 1 to 21. The median ratio between occupants and bedroom/sleeping area is 1.8 (IQR: 1.2 - 2.5, range: 0.1 - 7). (Data not tabulated)

Slightly more than half gave positive family history of TB. The median for the time lapse between the last episode in the family and the current episode was 48 months (IQR: 1 - 312 months).

Nearly 6% of respondents, all men, had history of substance misuse prior to diagnosis. About a fifth currently consumed alcohol. Among those who currently consume alcohol, three respondents drank several glasses daily, while the rest reported consuming 3 glasses on a weekly or monthly basis. More men smoked compared to women. One to 20 cigarettes were smoked a day (median of 5 cigarettes per day and IQR: 3 - 10) by current smokers.

Health facilities are fairly accessible and in most cases, travelling time to the nearest health facility took less than 30 minutes. Health clinics are also accessible where around 24% of the respondents walked to the nearest health clinics. Most rural respondents had to depend on the public transport to get to the nearest health facility or health provider. For those living in urban areas, more than half used their own transport for the same purpose. (Data not presented) Approximately 84% of the respondents have used a government health facility in the past. Approximately 73% preferred government facilities while around 17% preferred private practitioners. There were slight variations in health utilisation among men and women. Slightly more women preferred government clinic than men. In relation to household income, the higher the income level, the stronger, the preference for private practitioners. (Data not presented)

Respondents who usually go to government clinic for treatment would also do the same for their current illness (TB). Almost 90% of the respondents who usually sought treatment at government clinic had continued to do so for current illness (TB) while the remainder chose private practice. (Data not presented)

The perception among TB patients of government health facilities was good; 13.5% said the services were 'good', 63.2% agreed they were 'very good' and about 18.9% said 'excellent'. 5 patients (all of whom had patronised the facilities) perceived the services as not satisfactory and 7 chose not to make any comments.

6.4.2 Symptomatology

The commonest symptom was cough (reported by 92.2%), followed by loss of weight (84.8%), lethargy (80.4%), fever (75.3%) and loss of appetite (70.6%). Almost half of the respondents had coughed out blood.

More than half of the respondents have 3 to 4 respiratory symptoms. Almost 40% have all the constitutional symptoms of loss of weight, loss of appetite, fever, lethargy and insomnia. (Table 6.5)

Table 6.5: Frequency of respiratory and constitutional symptoms

Number of symptoms	Respiratory symptoms (col %)	Constitutional symptoms (col %)
None	9 (3)	9 (3)
1 - 2	123 (41.6)	44 (14.9)
3 - 4	164 (55.4)	125 (42.2)
≥ 5	NA*	118 (39.9)

* (only four respiratory symptoms)

The commonest symptom for which treatment was sought was cough while the least common was hemoptysis. The shortest median duration for symptoms before treatment was sought was hemoptysis followed by fever. (Table 6.6)

Table 6.6: Frequency and median durations for symptoms

Symptoms: sought treatment for	Frequency No (row %)	Frequency Yes (row %)	Median duration (IQR)(days)
Cough	39 (14.9)	222 (85.1)	30 (14 - 90)
Chest pain	165 (63)	97 (37)	30 (14 - 90)
Shortness of breath	147 (56.3)	114 (43.7)	30 (7 - 90)
Hemoptysis	183 (70.1)	78 (29.9)	7 (3 - 60)
Loss of appetite	133 (51)	128 (49)	30 (7 - 60)
Loss of weight	130 (49.8)	131 (50.2)	30 (14 - 60)
Fever	120 (46)	141 (54)	14 (7 - 30)
Lethargy	114 (43.7)	147 (56.3)	30 (7 - 60)

Results of sputum examination were available for 169 respondents and the 'maximum' reading of three or more specimens are tabulated in Table 6.7. Of these, almost two thirds had reading of more 50 bacteria per line. Only 157 chest x-ray results were available in the patient's case notes. Of these, almost 85% had moderate to advanced lesions.

Table 6.7: Results of sputum examination and chest x-ray

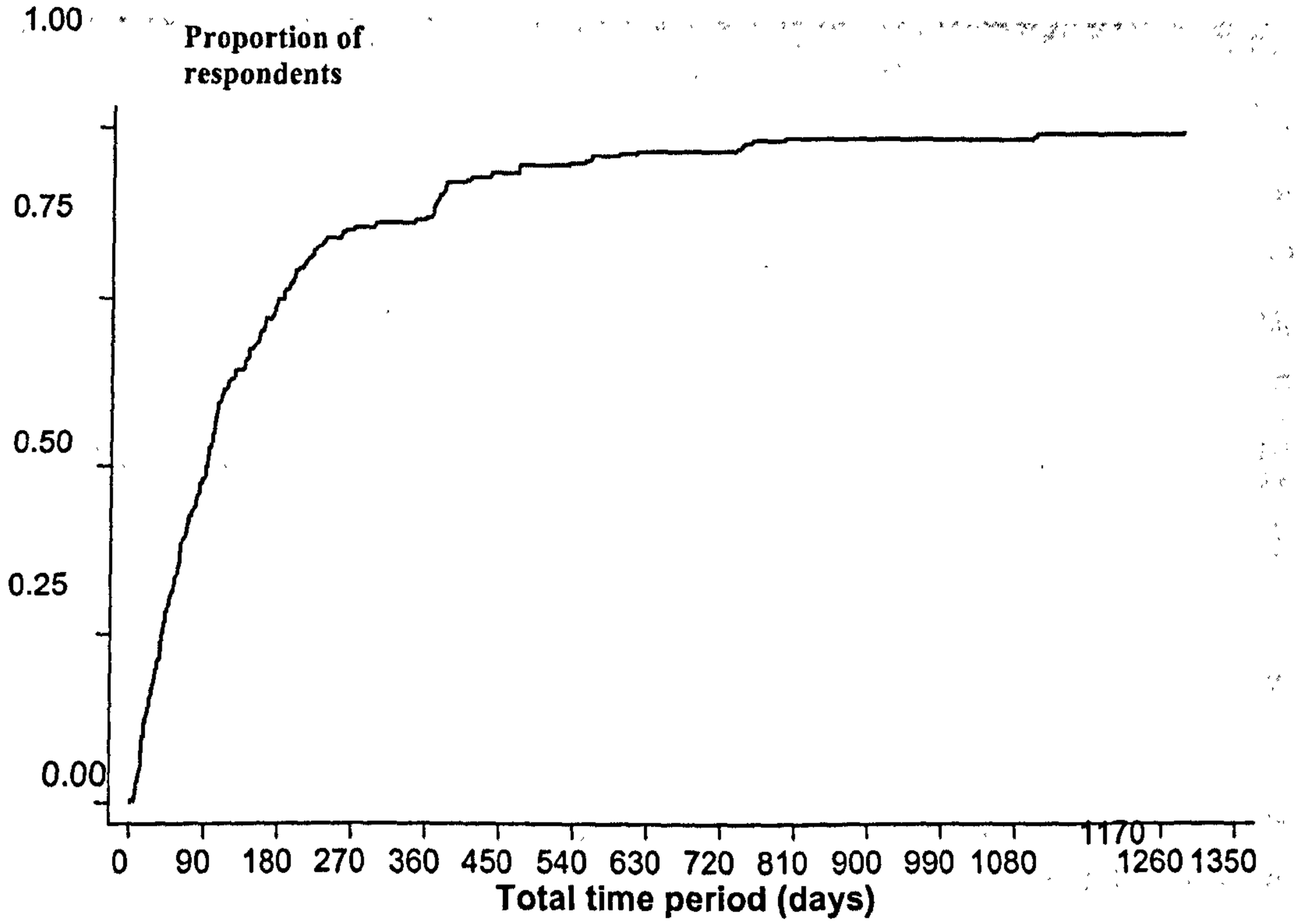
Variable	Frequency (col %)	Male (col %)	Female (col %)	p-value X^2
Results of sputum examination* (n=169)				
1 - 49/3L (1+)	37 (21.9)	24 (22)	13 (21.7)	
50/> 1L (2+)	6 (3.6)	1 (0.9)	5 (8.3)	
11 - 49/L (3+)	20 (11.8)	15 (13.8)	5 (8.3)	
> 50/L (4+)	106 (62.7)	69 (63.3)	37 (61.7)	0.07
Results of chest x-ray* (n=158)				
No lesion	1 (0.6)	0	1 (1.8)	
Minimal	23 (14.6)	15 (14.6)	8 (14.5)	
Moderately advanced	116 (73.4)	74 (71.8)	42 (76.4)	
Far advanced	18 (11.4)	14 (13.6)	4 (7.3)	0.36

* Classification based on the National Guideline [122]

6.5 Total time period

This time period is defined as the interval from the date of onset of symptoms to the date of starting treatment. Dates of symptoms onset have been calculated as described in 5.7.3. The dates of starting treatment were obtained from the patients' treatment cards. The median for total time period for 269 patients is 90 days, IQR: 38-176 days, range 1- 1281 days (Figure 6.2).

Figure 6.2: Kaplan Meier plot of total time period (days)



The time period comprise of 2 components: patient and doctor time periods. (Figure 5.1)

7 Chapter 7: Results of cross sectional study on explanatory factors for patient delay

This chapter presents the quantitative results of the study of explanatory factors for patient delay. The putative explanatory variables are described and then analysed for association with patient delay. Finally, multivariate analysis is performed for these explanatory factors for patient delay based on a hierarchical approach using the conceptual framework discussed in Figure 5.3.

7.1 Patient time period

The duration for each TB symptom were asked during the interview. The median for the maximum duration was 60 days, IQR: 21 -90 days, range; 1 - 1095 days. The maximum duration of one or more of the 4 major symptoms (cough, hemoptysis, fever and loss of weight) was used in the calculation for patient time period. For 90 respondents, although all 4 symptoms were reported, only one symptom contributed to the calculation of patient time period for half of this number while two symptoms contributed for a quarter of them. (Table 7.1)

There were 21 missing value for duration of symptoms as shown by the total number in Table 7.1. For 11 of these respondents, the period between when the patient first realised the symptoms to the time of seeking treatment was used. Using these periods, date of onset of symptoms could be generated. However, due to missing data for the date of seeking treatment, only 273 out of 296 respondents had both date of onset of symptoms and date of seeking treatment. One respondent was excluded because TB was an incidental finding when he sought treatment for accidental injuries, which made available data on patient time period for 272 respondents for further analysis.

Table 7.1: Number of symptoms reported and contribution to calculation of time period

Number of symptoms* contributing to calculation of patient time period	Number of the symptoms* reported				
	One symptom (col %)	Two symptoms (col %)	Three symptoms (col %)	Four symptoms (col %)	Total (col %)
One symptom	9 (100)	33 (67.3)	77 (60.6)	49 (54.4)	168 (61.1)
Two symptoms	0	16 (32.7)	34 (26.8)	22 (24.4)	72 (26.2)
Three symptoms	0	0	16 (12.6)	12 (13.3)	28 (10.2)
Four symptoms	0	0	0	7 (7.8)	7 (2.5)
Total	9	49	127	90	275

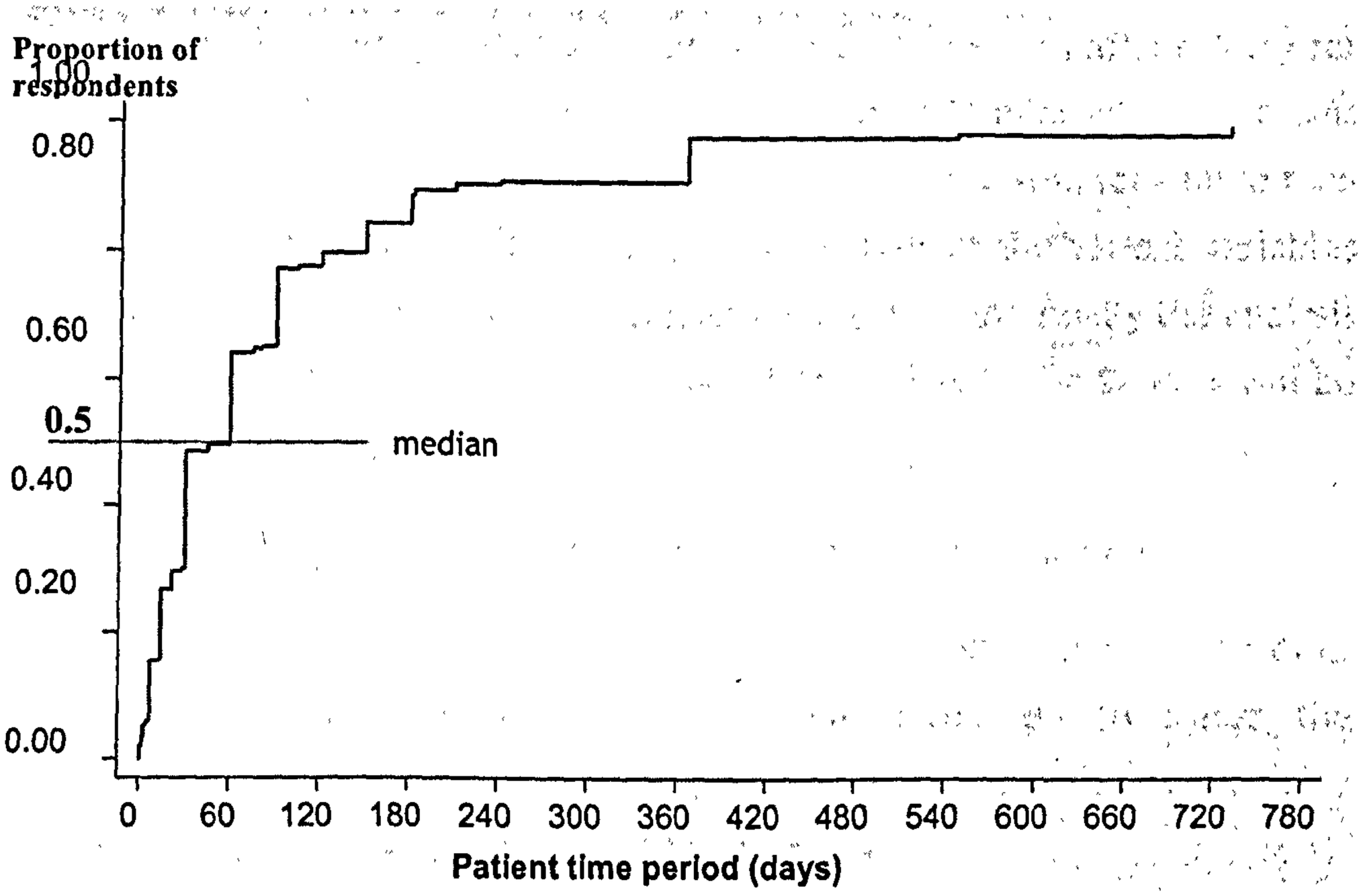
* - cough, hemoptysis, loss of weight and fever

Among these 272 respondents, 200 of them (73.5%) first sought treatment at government clinics, 66 (24.3%) at private clinics, 4 (1.5%) bought medicine from pharmacies and one respondent each first used traditional medicine or traditional herbalist.

The distributions of sex, age and race were similar for respondents where a patient time period could be defined (n=272) compared with respondents where a patient time period could not be defined (n=24).

The median for patient time period was 60 days (IQR: 14 - 90 days, range 1 - 1095 days). (Figure 7.1)

Figure 7.1: The Kaplan-Meier plot of patient time period (days)



Note: 2 respondents with patient time period of 1095 days were not shown in the graph above.

The Kaplan-Meier plot of patient time period shows large steps at 30 (n=50, 18.4%), 60 (n=39, 14.3%) and 90 (n=32, 11.8%) days indicating clustering of patient time periods at these times.

Thirty two respondents had patient time period exceeding 15 months (456 days), three quarters were men. Approximately 80% of them resided in the rural area and just over half had a household income of more than USD132. Almost three quarters of them sought government health facility for this current illness (TB) for which the main presenting symptom was cough.

The respondents were also asked how long it took them from deciding to seek treatment to actually go to the place for treatment for any of the symptoms which prompted them to seek treatment. Approximately 84% took a day following decision to actually seek treatment while the longest period was 14 days (9 respondents).

7.2 Patient delay

This section will present analysis of explanatory factors for patient delay for two cut-off points: those who took more than 30 days from onset of symptoms to seeking treatment from any health providers and those who took more than 90 days will be described. Firstly, univariate analysis of the various variables will be presented followed by the multivariate analysis and finally the analysis of the secondary outcome which is patient delay of more than 90 days will be described.

7.2.1 Univariate analysis for patient delay of more than 30 days

Among the 272 respondents, 51.8% had patient delay (95% CI: 45.9 - 57.8) of more than 30 days. Univariate analysis was performed to assess the association of distal, intermediate and proximal variables with patient delay and the results are shown in Table 7.2 to Table 7.4.

a. Socio-demographic factors and social history

These factors formed the distal determinants in the conceptual framework described in Figure 5.3.

Table 7.2: Univariate analysis of socio-demographic and social history factors (distal determinants) and patient delay

Variable	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Location						
Urban	59 (21.7)	30	29 (49.1)	1		
Rural	213 (78.3)	101	112 (52.6)	1.15	0.64 - 2.04	0.64
Sex						
Male	172 (63.2)	85	87 (50.6)	1		
Female	100 (36.8)	46	54 (54)	1.15	0.70 - 1.88	0.59
Age group (years)						
18 - 29	82 (30.1)	46	36 (43.9)	1		
30 - 39	51 (18.8)	18	33 (64.7)	2.34	1.14 - 4.82	
40 - 49	55 (20.2)	29	26 (47.3)	1.14	0.58 - 2.27	
50 - 59	38 (14.0)	16	22 (57.9)	1.76	0.81 - 3.82	
≥ 60	46 (16.9)	22	24 (52.2)	1.39	0.68 - 2.88	0.16
Race						
KDM	128 (47.1)	65	63 (49.2)	1		
Bajau	48 (17.6)	27	21 (43.8)	0.80	0.41 - 1.56	
Other indigenous	73 (26.8)	28	45 (61.6)	1.66	0.92 - 2.98	
Chinese	14 (5.1)	6	8 (57.1)	1.37	0.45 - 4.19	
Others	9 (3.3)	5	4 (44.4)	0.83	0.21 - 3.21	0.31

Variable	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Marital status						
Single	62 (22.8)	33	29 (46.8)	1		
Married	186 (68.4)	86	100 (53.8)	1.32	0.74 - 2.35	
Others	24 (8.8)	12	12 (50)	1.13	0.44 - 2.92	0.62
Education (n_{miss}=1)						
None	56 (20.7)	25	31 (55.4)	1		
Primary	96 (35.4)	50	46 (47.9)	0.74	0.38 - 1.44	
Secondary	99 (36.5)	45	54 (54.6)	0.97	0.50 - 1.87	
Tertiary & above	20 (7.4)	10	10 (50)	0.81	0.29 - 2.24	0.76
Household income (n_{miss}=8)						
No fixed income	17 (6.4)	9	8 (47.1)	0.75	0.26 - 2.11	
< USD 132	73 (27.7)	38	35 (48)	0.77	0.42 - 1.43	
USD 132 - 263	82(31.1)	39	43 (52.4)	0.93	0.51 - 1.68	0.84
> USD 263	92 (34.8)	42	50 (54.4)	1		
Own house						
No	98 (36)	48	50 (51)	1		
Yes	174 (64)	83	91 (52.3)	1.05	0.64-1.73	0.84
Own transport						
No	179 (65.8)	92	87 (48.6)	1		
Yes	93 (34.2)	39	54 (58.1)	1.46	0.88 - 2.43	0.14
Own Land(n_{miss}=1)						
No	131 (48.3)	62	69 (52.7)	1		
Yes	140 (51.7)	69	71 (50.7)	0.92	0.57-1.49	0.75
Livestock						
No	175 (64.3)	87	88 (50.3)	1		
Yes	97 (35.7)	44	53 (54.6)	1.19	0.72-1.96	0.49
TV/radio(n_{miss}=4)						
No	41 (15.3)	19	22 (53.7)	1		
Yes	227 (84.7)	108	119 (52.4)	0.95	0.49-1.85	0.88
Type of house						
'Village'	215 (79)	99	116 (53.9)	1		
Residential	29 (10.7)	12	17 (58.6)	1.21	0.55 - 2.65	
Others# .	28 (10.3)	20	8 (28.6)	0.34	0.14 - 0.81	0.03
Alcohol intake (n_{miss}=1)						
Never	98 (36.2)	51	47 (48)	1		
Past intake	140 (51.6)	65	75 (53.6)	1.25	0.75 - 2.10	
Current	33 (12.2)	15	18 (54.5)	1.30	0.59 - 2.87	0.65
History of smoking (n_{miss}=1)						
Never	114 (42.1)	58	56 (49.1)	1		
Ex-smoker	121 (44.6)	55	66 (54.5)	1.24	0.74 - 2.07	
Current	36 (13.3)	18	18 (50)	1.03	0.49 - 2.19	0.69
History of drug abuse (n_{miss}=1)						
No	254 (93.7)	123	131 (51.6)	1		
Yes	17 (6.3)	8	9 (52.9)	1.06	0.39 - 2.83	0.91

* p-value from likelihood ratio test
# Refers to squatters, quarters, long house and others in Table 6.4

Household income was used in the univariate analysis instead of individual income as this was a better measurement of wealth. For most socio-demographic variables, the data were compatible with no association with patient delay. Although there was variation across the different age group, there appeared to be no trend in the odds ratios for age group.

b. Medical and family history

Based on the conceptual framework (Figure 5.3), these variables are the intermediate variables. As with socio-demographic variables, the data were also compatible with no association with patient delay.

Table 7.3: Univariate analysis of medical, family and social history factors (intermediate determinants) and patient delay

Covariate	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Mobility problem (n_{miss}=1)						
No	239 (87.9)	114	125 (52.3)	1		
Yes	33 (12.1)	17	16 (48.5)	0.86	0.41 - 1.78	0.68
Co-morbidity						
No	184 (67.6)	94	90 (48.9)	1		
Yes	88 (32.4)	37	51 (57.9)	1.44	0.86 - 2.41	0.16
Family history of TB (n_{miss}=1)						
No	132 (48.7)	58	74 (56.1)	1		
Yes	139 (51.3)	72	67 (48.2)	0.73	0.45 - 1.18	0.20

* p-value from likelihood ratio test

c. Health care utilisation

Some of the variables in this group formed the intermediate determinants while treatment choice for current illness (TB) and those related to this variable (travelling time and mode of transportation) formed the proximal determinants. (Figure 5.3)

There is an association between usual first place for treatment and patient delay. Those who preferred non-government health facility had double the odds of patient delay compared to those who preferred government health

facility. However, this association was not replicated in relation to choice of facility for the current illness (TB) although the pattern is similar. Although, there was no linear trend for frequency of use of government facility over the past year, those who had used the government clinic once or twice over the past year had reduced odds ratio compared to those who had never used government facility before. However, this was not true for three or more usage of government facilities over the past year.

Table 7.4: Univariate analysis of health care utilisation factors (intermediate and proximal determinants) and patient delay

Covariate	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Ever use government health facility						
Yes	230 (84.6)	114	116 (50.4)	1		
No	42 (15.4)	17	25 (59.5)	1.44	0.74 - 2.82	0.28
Number of times used government health facility over past year (n_{miss}=3)						
Never use	42 (15.6)	17	25 (59.5)	1		
None	49 (18.2)	19	30 (61.2)	1.07	0.46 - 2.49	
1 - 2 times	65 (24.2)	41	24 (36.9)	0.40	0.18 - 0.88	
3 or more	113 (42)	52	61 (54)	0.80	0.39 - 1.64	0.03
Travel time to the nearest clinic (n_{miss}=2)						
< 15 min	144 (53.3)	71	73 (50.7)	1		
15 - 29 min	89 (33)	40	49 (55.1)	1.19	0.70 - 2.02	
≥ 30 min	37 (13.7)	19	18 (48.7)	0.92	0.45 - 1.90	0.74
Transport to the nearest clinic						
Public transport	123 (45.2)	57	66(53.7)	1		
Own transport	101(37.1)	47	54 (53.5)	0.98	0.58 - 1.68	
Walk	48(17.7)	27	21 (43.8)	0.24	0.34 - 1.31	0.47
Travel time to the nearest hospital (n_{miss}=1)						
< 15 min	49 (18.1)	21	28 (57.1)	1		
15 - 29 min	98 (36.2)	44	54 (55.1)	0.92	0.46 - 1.84	
≥ 30 min	124 (45.7)	65	59 (47.6)	0.68	0.35 - 1.33	0.39

Covariate	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Transport to the nearest hospital						
Public transport	164 (60.3)	81	83 (50.6)	1		
Own transport	102 (37.5)	47	55(53.9)	1.14	0.69 - 1.87	
Walk	6(2.2)	3	3 (50)	0.97	0.19 - 4.98	0.87
Usual first choice for treatment (n_{miss}=1)						
Gov facility	198 (73.1)	104	94 (47.5)	1		
Others	73 (26.9)	27	46 (63.0)	1.88	1.08 - 3.29	0.02
Treatment choice for current illness (TB)						
Gov clinic	200 (73.5)	102	98 (49.0)	1		
Others	72 (26.5)	29	43 (59.7)	1.54	0.89 - 2.67	0.12
Travel time to treatment choice						
< 15 min	96 (35.3)	41	55 (57.3)	1		
15 - 29 min	95 (34.9)	48	47 (49.5)	0.73	0.41 - 1.29	
≥ 30 min	81 (29.8)	42	39 (48.2)	0.69	0.38 - 1.25	0.41
Transport to the treatment choice						
Public Transport	134(49.3)	62	72 (53.7)	1		
Own transport	112(41.2)	56	56(50)	0.56	0.52 - 1.42	
Walk	26(9.6)	13	13 (50)	0.73	0.37 - 1.99	0.83

* p-value from likelihood ratio test

7.2.2 Multivariate analysis for patient delay of more than 30 days

Sex and age group were considered *a priori* confounders and retained in all the models. Given their expected importance, education level and household income were included and examined for their role as potential confounders despite the fact that their association with the patient delay in the univariate analysis gave p-values greater than 0.2.

In addition to these variables, all variables with p-value ≤ 0.2 in the univariate analysis were considered in the multivariate analysis. At the distal level of these were types of house. Co-morbidity, family history of TB, number of

times government facility was used over the past year and usual first place for treatment were variables at the intermediate level. There was only one variable at the proximal level: treatment choice for current illness (TB).

a. Multivariate analysis with distal determinants - modelling stage 1

As shown in Table 7.5, odds ratios for sex, age group (those 60 and above) and for those with secondary education and above showed more than 10% change in the point estimates. Household income was dropped from the model as its inclusion did not change much the other point estimates and the p-value for its association with patient delay, using likelihood ratio test, was 0.64. The decision was to retain the other variables and the type of house for the next step which would include the intermediate variables.

Table 7.5: Multivariate analysis for patient delay by including distal determinants (n=271)

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value*
Sex					
Male	1		1		
Female	1.15	0.70 - 1.88	1.29	0.74 - 2.24	0.37
Age group (years)					
18 - 29	1		1		
30 - 39	2.34	1.14 - 4.82	2.39	1.12 - 5.08	
40 - 49	1.14	0.58 - 2.27	1.13	0.54 - 2.34	
50 - 59	1.76	0.81 - 3.82	1.91	0.80 - 4.59	
≥ 60	1.39	0.68 - 2.88	1.59	0.62 - 4.07	0.15
Education					
None	1		1		
Primary	0.74	0.38 - 1.44	0.86	0.39 - 1.89	
Secondary & above	0.97	0.50 - 1.87	1.46	0.60 - 3.51	0.25
Type of house					
'Village'	1		1		
Residential	1.21	0.55 - 2.65	1.06	0.45 - 2.46	
Others+	0.34	0.14 - 0.81	0.28	0.11 - 0.71	0.01

* p-value from likelihood ratio test

+ Refers to squatters, quarters, long house and others in Table 6.4

b. Multivariate analysis with distal and intermediate determinants - stage 2

By adding the intermediate variables into the model one at a time, co-morbidity was excluded as the p-value did not reach the predetermined value

of 0.1. Family history of TB was retained although the p-value was 0.32 as it changed the point estimates of female and age group of 30 - 39 years by about 10%. Number of times government facility was used was retained as its inclusion increased the odds ratio of usual first choice of treatment and some of the age group despite the p-value exceeding 0.1.

Table 7.6: Multivariate analysis for patient delay, including distal and intermediate determinants (n=266)

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value*
Sex					
Male	1		1		
Female	1.15	0.70 - 1.88	1.41	0.78 - 2.53	0.25
Age group (years)					
18 - 29	1		1		
30 - 39	2.34	1.14 - 4.82	2.62	1.17 - 5.87	
40 - 49	1.14	0.58 - 2.27	1.02	0.47 - 2.22	
50 - 59	1.76	0.81 - 3.82	1.57	0.62 - 3.99	
≥ 60	1.39	0.68 - 2.88	1.38	0.51 - 3.76	0.14
Education					
None	1		1		
Primary	0.74	0.38 - 1.44	0.74	0.33 - 1.67	
Secondary & above	0.97	0.50 - 1.87	1.13	0.44 - 2.85	0.40
Type of house					
'Village'	1		1		
Residential	1.21	0.55 - 2.65	0.86	0.36 - 2.08	
Others	0.34	0.14 - 0.81	0.27	0.11 - 0.71	0.02
Family history of TB					
No	1		1		
Yes	0.73	0.45 - 1.18	0.77	0.45 - 1.32	0.32
Usual first choice for treatment					
Gov facility	1		1		
Others	1.88	1.08 - 3.29	2.28	1.03 - 5.06	0.04
Number of times used government health facility over past year					
Never use	1		1		
None	1.07	0.46 - 2.49	1.45	0.51- 4.10	
1 - 2 times	0.40	0.18 - 0.88	0.65	0.24 - 1.75	
3 or more	0.80	0.39 - 1.64	1.30	0.47 - 3.58	0.16

* p-value from likelihood ratio test

c. Multivariate analysis using distal, intermediate and proximal determinants - stage 3

Including the only proximal variable identified in the univariate analysis (treatment choice for current illness (TB)) into the multivariate model did not change any of the point estimates. In addition, the variable was not associated with patient delay at the 0.1 significance level and therefore was not retained in the model. The variables that were not retained earlier were introduced again one at a time to see whether they were associated with patient delay after adjusting for other variables.

The final model is as shown in Table 7.6 above. After adjusting for confounders and mediating factors, only the usual first choice for treatment remained associated with patient delay. Patients whose usual first place for treatment was non-government health facilities had more than double the odds of patient delay than those whose first choice was government clinics. In addition, those aged between 30 to 39 years old were 2.6 times more likely to have patient delay compared to the baseline group of 18 to 29 years old (CI: 1.17 - 5.87). However, no increase of odds ratio in older age group was seen. Those who lived in 'other' type of house (not 'village' and not residential) were less likely to have patient delay compared to those who lived in 'village' houses (adjusted OR: 0.27, CI: 0.11 - 0.71) but not in those living in residential housing. No important association was seen in this dataset with education level or with female sex though there was a tendency for a U-shaped relationship with no education and higher than secondary education and being female having a higher odds of delay.

The duration for 4 symptoms (cough, hemoptysis, fever and loss of weight) was used in the calculation of patient time period. For 168 respondents (Table 7.1), only one of the 4 symptoms contributed to the calculation and hemoptysis was the one contributing symptom for 12 of these respondents. Since hemoptysis was associated with patient delay in 2 studies[66, 83], it was included in the final model to see whether it was associated with patient delay after adjusting for confounding effects and found that it was not. (Data not shown)

7.2.3 Analysis of patient delay of more than 90 days

The secondary outcome for patient delay uses a different cut-off point of 90 days. This section presents the univariate analysis and multivariate analysis which uses the same methods as explained for patient delay of more than 30 days. Of the 272 respondents, 23.5% (95% CI: 18.4 - 28.6) had patient time period of more than 90 days.

a. Univariate analysis

The socio-demographic variables were compatible with no association with patient delay of more than 90 days. Those with co-morbidity had double the odds of patient delay of more than 90 days; OR of 1.92, 95% CI from 1.07 to 3.44) compared to those without. Modes of transportation to the nearest clinic and treatment choice for current illness (TB) had weak association with patient delay of more than 90 days. Those who used own transport or walk to the nearest clinic or treatment choice for current illness were less likely to have patient delay of more than 90 days; p-value of 0.05 for both. The detailed results of this analysis are summarised in Appendix 8.

b. Multivariate analysis for patient delay of more than 90 days

For the multivariate analysis, the variables at the distal level were sex, age group, educational level, household income, own livestock and type of house. At the intermediate level were co-morbidity, transport to the nearest clinic and usual place for treatment. Transport to treatment choice for current illness (TB) was the only variable at the proximal level that was retained in the model because the p-value was $\leq$ 0.1. As with multivariate analysis for patient delay of 30 days, sex and age group were retained in all models while education and household income was included one at a time as they were considered potential confounders. Since transport to the nearest clinic and transport to treatment choice for current illness (TB) was correlated, the former was not included in the multivariate analysis.

In the multivariate analysis (Table 7.7), usual first choice of place for seeking treatment was found to be associated with patient delay of more than 90 days.

Those who usually sought treatment at non-government facilities were 2.3 (CI: 1.11-4.68) times more likely to have patient delay of more than 90 days compare to those who usually preferred government clinics. This finding is similar to the multivariate analysis for patient delay of more than 30 days. Those aged 30 to 39 years also had double the odds (CI: 0.91-4.68) of patient delay of more than 90 days compared to the baseline age group of 18 - 29 years old. Finally, there was weak evidence that those who owned livestock and had other medical conditions were also almost twice more likely to have patient delay of more than 90 days (adjusted OR: 1.88, CI: 0.98 - 3.63 and adjusted OR: 1.95, CI: 0.97 - 3.91). It was found that gender and education level were compatible with no association with 'extreme' patient delay.

Table 7.7: Multivariate analysis for patient delay of more than 90 days (n=262)

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value
Sex					
Male	1		1		
Female	1.13	0.64 - 2.02	1.18	0.59 - 2.34	0.64
Age group (years)					
18 - 29	1		1		
30 - 39	1.86	0.82 - 4.24	2.27	0.91 - 5.69	
40 - 49	0.99	0.41 - 2.40	1.02	0.38 - 2.75	
50 - 59	2.60	1.10 - 6.19	1.92	0.65 - 5.62	
≥ 60	1.24	0.51 - 3.04	0.91	0.24 - 3.43	0.23
Education					
None	1		1		
Primary	0.76	0.36 - 1.64	0.69	0.25 - 1.87	
Secondary & above	0.84	0.41 - 1.74	0.90	0.28 - 2.90	0.66
Household income					
No fixed income	1		1		
< USD 132	0.78	0.24 - 2.53	0.86	0.23 - 3.20	
≥ USD 132	0.67	0.22 - 2.02	0.73	0.20 - 2.71	0.86
Location					
Urban	1		1		
Rural	1.93	0.89 - 4.21	1.17	0.41 - 3.29	0.77
Own livestock					
No	1		1		
Yes	1.57	0.88 - 2.78	1.85	0.96 - 3.56	0.06
Type of house#					
'Village'	1		1		
Others	0.39	0.17 - 0.90	0.55	0.19 - 1.64	0.29
Co-morbidity					
No	1		1		
Yes	1.92	1.07 - 3.44	1.90	0.95 - 3.79	0.06
Usual first choice for treatment					
Gov facility	1		1		
Others	1.60	0.87 - 2.94	2.28	1.11 - 4.68	0.02
Transport to treatment choice					
Public transport	1		1		
Own transport	0.51	0.28 - 0.94	0.48	0.24 - 0.96	
Walk	0.43	0.14 - 1.32	0.28	0.07 - 1.09	0.03

* p-value from likelihood ratio test

Type of housing was regrouped: residential and others were grouped into one due to the small numbers in one of the cells.

8 Chapter 8: Results of cross sectional study on explanatory factors for doctor delay

Variables related to health provider such as sputum examination at first visit to government clinics and repeat visit to first provider will be described in this chapter. These variables were also analysed for association with doctor delay as with all the variables listed in Table 6.4. In the multivariate analysis, variables related to health provider and symptoms were defined as proximal determinants. Socio-demographic and social history remained as distal determinants while the other variables in Figure 5.4 were defined as intermediate determinants. This multivariate analysis, based on the conceptual framework in 5.7.6, was performed for both doctor delay of more than 14 days and 60 days.

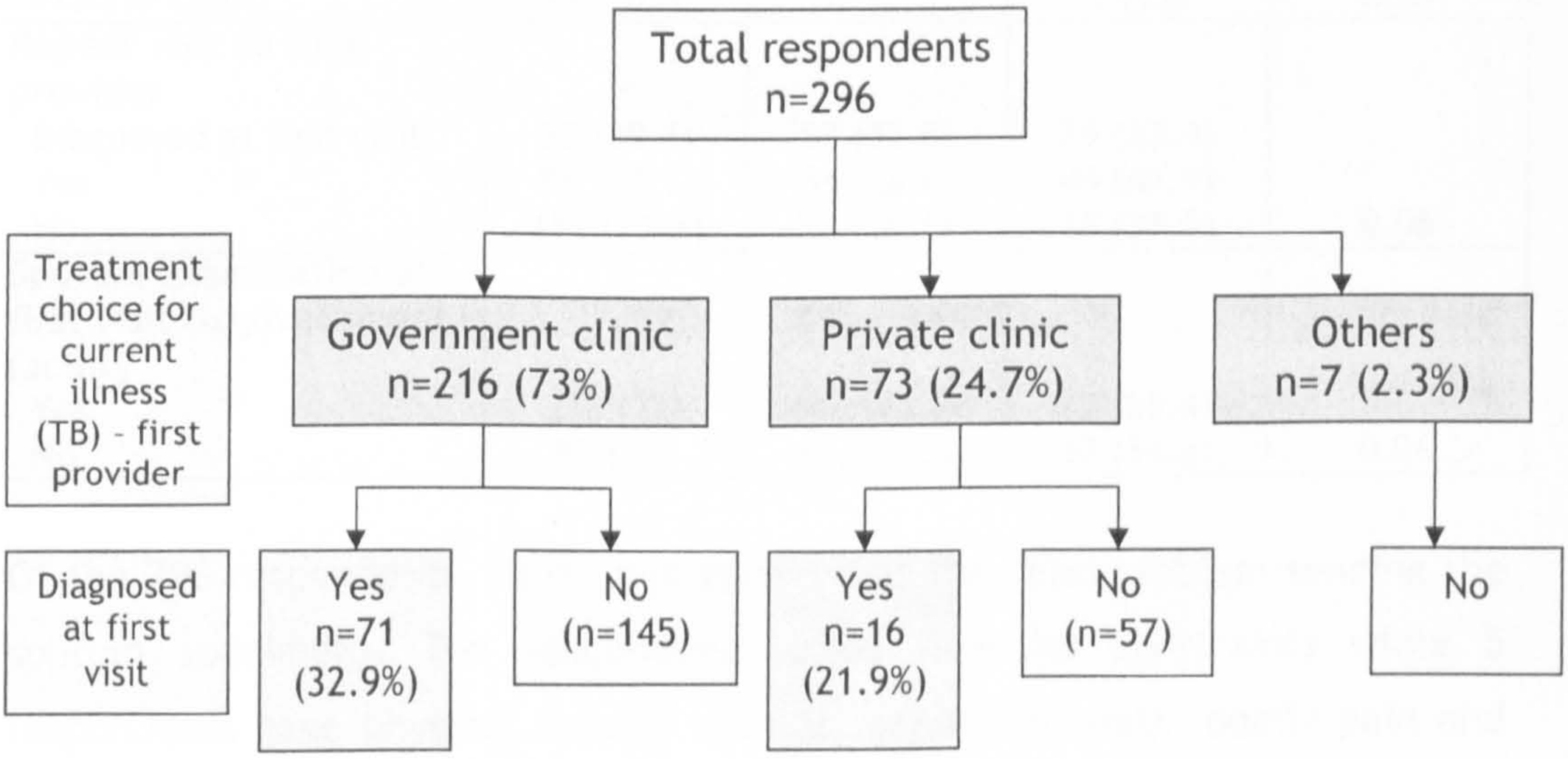
8.1 Diagnosis by health provider

As revealed in this study, almost all respondents sought treatment from either government or private clinics where diagnosis of TB was possible. However, most diagnoses made at private clinics were based on clinical presentations and/or chest x-ray. Smear results were also used for diagnosis, though rarely. Following such diagnosis, patients would be referred to the government clinic for treatment. Patients who had not had sputum examinations or whose examinations were incomplete i.e. only one specimen, the test would be initiated or repeated. Patients may choose to be treated at private clinic, in which case, they would have to pay for treatment. As required by the law, the case would be notified to the nearest district health office and registered in the TB Registry for the district. This TB Registry was also checked during the recruitment process to ensure that even those who were on treatment at private clinics were recruited in the study. During the study period, there were no such cases.

In this study; 30% of respondents (87/289) were diagnosed at their first visit to a doctor (either private or government). Almost a third of those who sought treatment at government clinics were diagnosed at their first visit while only

approximately 22% of those who went to private clinics were diagnosed at their first visit. (Figure 8.1)

Figure 8.1: Flow chart of case diagnosis by health provider



Almost 35% of the respondents had more than one visit to the same provider. There is association between repeat visit and sex; more women had repeat visit to the first provider compared to men. (Table 8.1)

Data on sputum examination at the government clinic was collected. Almost 72% of the respondents were requested to provide sputum samples at the first consultation at a government facility. (Table 8.1)

According to the national guideline, those with cough of more than 2 weeks should be subjected to sputum examination and therefore should be more likely to be diagnosed than those with cough of shorter duration. An analysis of the 296 respondents revealed that 190 respondents (64%) had cough of more than 14 days. Of these, 132 respondents first went to a government doctor and 53 went to a private doctor. Only a third was diagnosed at the first visit to a government doctor and approximately 23% by a private doctor. (Data not presented)

Table 8.1: Health provider factors

Variable	Frequency (col %)	Male (col %)	Female (col %)	p-value X^2
Diagnosis at first visit (n=87)				
Government clinic	71 (81.6)	49 (79)	22 (88)	
Private clinic	16 (18.4)	13 (21)	3 (12)	0.33
Repeat visit to first provider				
Diagnosed at first visit	87 (29.4)	62 (32.8)	25 (23.4)	
Yes	98 (33.1)	54 (28.6)	44 (41.1)	
No	111 (37.5)	73 (38.6)	38 (35.5)	0.06
Sputum examination at first visit to government facility				
Yes	213 (72)	143 (75.7)	70 (65.4)	
No	83 (28)	46 (24.3)	37 (34.6)	0.06

Of the 296 respondents, thirty two stated that they had problem sending the sputum specimens. Ten respondents cited financial constraints while 5 respondents gave physical reasons such as inability to walk, bodily pain and breathlessness as the problems in sending the specimens. Four said they had transportation problems and 8 respondents had financial or other problems such as inability to leave work or family. Overall, 11 respondents had to submit more than 3 samples and only one of them was in this group who had problems sending specimen.

Despite the problems mentioned by the respondents, 98% managed to send their specimens in less than 4 days. Of the 4 respondents who submitted their specimens between 4 to 7days after the request, one was due to transportation problem and another had family problem during the period. For the remaining two, no reason was given for the delay.

All respondents had a chest x-ray examination; almost 96% chest x-rays were performed at the government health facility while the rest were done at private clinics. Nearly all (98%) chest x-rays were carried out within 48 hours after they were ordered. One respondent whose chest x-ray was performed after 4 days said that the reason was because the technician has gone on leave.

Almost a fifth were hospitalised prior to treatment, a third in the district of Kudat and 15% at Queen Elizabeth Hospital, the State referral hospital in Kota Kinabalu.

8.2 Non-governmental practitioner time period

Non-governmental practitioner time period was calculated as the interval between the first presentations to any provider to the consultation at a government clinic. This analysis is initially restricted to 80 respondents whose first consultation was not at a government facility. However, dates of seeking treatment at government clinic were only available for 72 respondents. Another 6 respondents had missing data for date of seeking treatment at first provider and one respondent had a date of seeking government clinic which was earlier than date of seeking first provider and therefore excluded. Thus, 65 respondents were available for analysis.

The median period was 15 days with IQR of 5- 68 days and ranges from 0 - 780 days (Table 8.2).

Table 8.2: Treatment choice among those whose first visit was to a non-government health facility

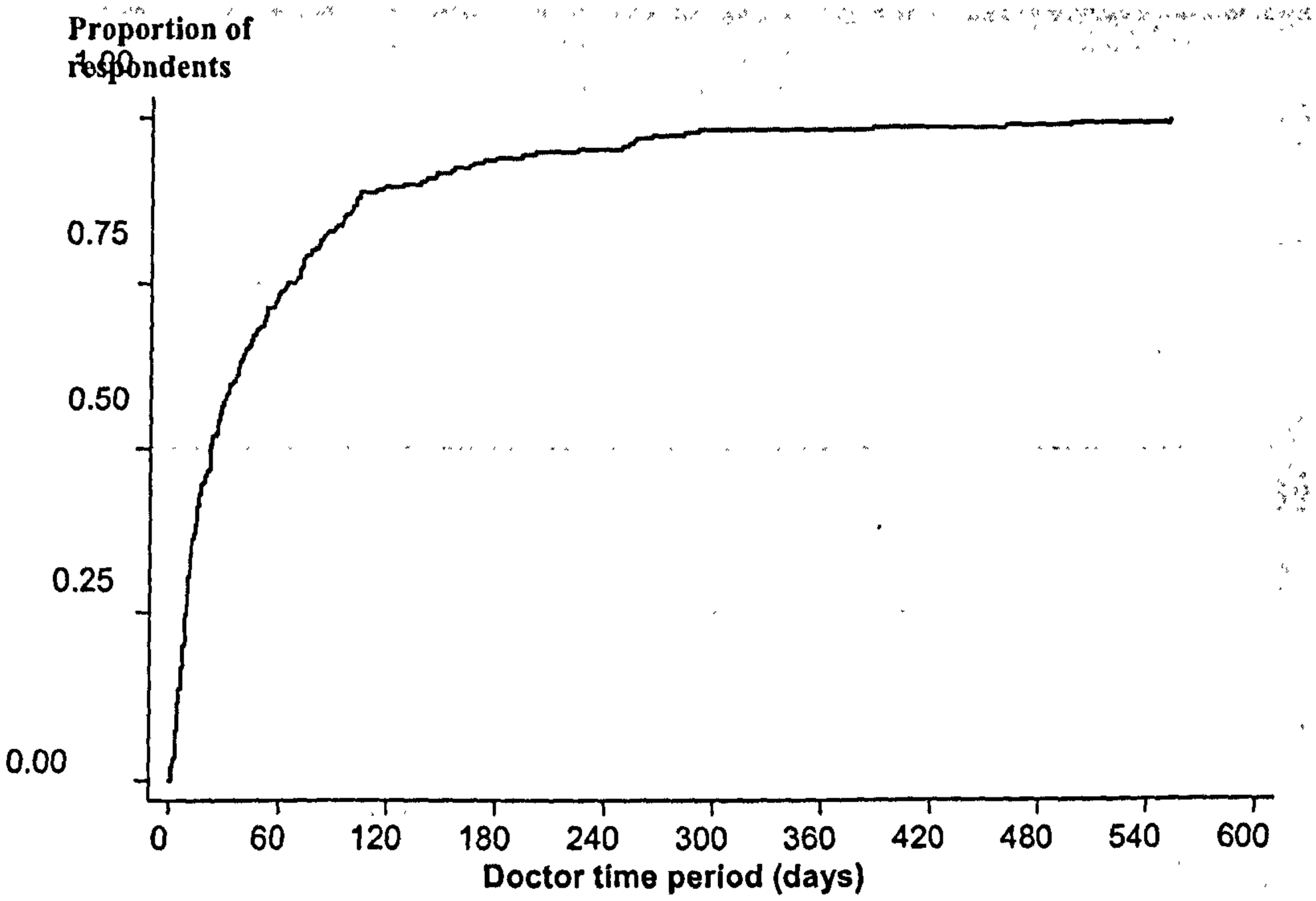
Treatment choice of first visit	Number of respondent	Median (days)	IQR (days)	Range (days)
Private clinic	59	13	3 - 69	0 - 550
Pharmacy	4	22.5		21 - 29
Traditional healer	1	780		
Traditional herbalist	1	15		

8.3 Doctor time period

The doctor time period is the time lapse between the first consultations with a medical doctor (government or private) to the start of treatment. Data for date of seeking treatment was missing for 19 respondents (13 for those who sought government clinics and 6 for those who sought private clinics). In addition, 17 had dates of seeking treatment that were after the date of starting treatment (14 for those who sought government clinics and 3 for those who sought private clinics) thus leaving data for 260 respondents for further analysis.

The median doctor time period for the 260 respondents was 20 days (IQR: 7 - 59 days, range 0 - 551days). (Figure 8.2)

Figure 8.2: Kaplan Meier plot of doctor time period (days)



8.4 Doctor delay

Doctor delay is defined as those who were put on treatment more than 14 days after seeing a doctor for their symptoms. Of the 260 respondents, 57.3% had doctor delay (95% CI: 51.2 - 63.3).

8.4.1 Univariate analysis for doctor delay of more than 14 days

This section presents results of the univariate analysis to assess the association of distal, intermediate and proximal variables with doctor delay based on the conceptual framework described in Figure 5.4.

a. Socio-demographic factors and social history

There was no pattern across age group with doctor delay. Those who owned transport were almost twice as likely to have doctor delay compared to those who did not own transport. In addition, those who owned land had 1.5 the odds of doctor delay compared to those who did not.

Table 8.3: Univariate analysis of socio-demographic and social history factors (distal determinants) and doctor delay

Variable	n (col %)	No delay	Doctor delay (row %)	OR	95% CI	p-value*
Location						
Urban	60(23.1)	29	31 (51.7)	1		
Rural	200 (76.9)	82	118 (59)	1.35	0.78 - 2.41	0.31
Sex						
Male	166 (63.8)	74	92 (55.4)	1		
Female	94 (36.2)	37	57 (60.6)	1.24	0.74 - 2.08	0.41
Age group (years)						
18 - 29	77 (29.6)	37	40 (51.9)	1		
30 - 39	50 (19.2)	20	30 (60)	1.39	0.67 - 2.85	
40 - 49	54 (20.8)	21	33 (61.1)	1.45	0.72 - 2.95	
50 - 59	37 (14.2)	18	19 (51.3)	0.98	0.45 - 2.14	
≥ 60	42 (16.2)	15	27 (64.3)	1.67	0.77 - 3.61	0.60
Race						
KDM	122 (46.9)	46	76 (62.3)	1		
Bajau	46 (17.7)	22	24 (52.2)	0.66	0.33 - 1.31	
Other indigenous	69 (26.5)	32	37 (53.6)	0.70	0.38 - 1.27	
Chinese	14 (5.4)	8	6 (42.9)	0.45	0.15 - 1.39	
Others	9 (3.5)	3	6 (66.7)	1.21	0.29 - 5.07	0.46
Marital status						
Single	60 (23.1)	28	32 (53.3)	1		
Married	181 (69.6)	74	107 (59.1)	1.26	0.70 - 2.28	
Others	19 (7.3)	9	10 (52.6)	0.97	0.34 - 2.73	0.67
Education (n_{miss}=1)						
None	52 (20.1)	25	27 (51.9)	1		
Primary	90 (34.7)	38	52 (57.8)	1.27	0.64 - 2.52	
Secondary	99 (38.2)	37	62 (62.6)	1.55	0.79 - 3.06	
Tertiary & above	18 (6.9)	10	8 (44.4)	0.74	0.25 - 2.18	0.39
Household income (n_{miss}=7)						
No fixed income	15 (5.9)	5	10 (66.7)	1		
< USD 132	71 (28.1)	28	43 (60.6)	0.77	0.24 - 2.48	
USD 132 - 263	77 (30.4)	37	40 (51.9)	0.54	0.17 - 1.73	
> USD 263	90 (35.6)	37	53 (58.9)	0.72	0.23 - 2.27	0.61
Own house						
No	93 (35.8)	44	49 (52.7)	1		
Yes	167 (64.2)	67	100 (59.9)	1.34	0.80 - 2.23	0.26
Own transport						
No	169 (65)	81	88 (52.1)	1		
Yes	91 (35)	30	61 (67)	1.87	1.10 - 3.18	0.02
Own Land(n_{miss}=1)						
No	126 (48.6)	61	65 (51.6)	1		
Yes	133 (51.4)	50	83 (62.4)	1.56	0.95 - 2.56	0.08
Livestock						
No	170 (65.4)	74	96 (56.5)	1		
Yes	90 (34.6)	37	53 (58.9)	1.10	0.66 - 1.85	0.71
TV/radio(n_{miss}=4)						
No	37 (14.5)	20	17 (45.9)	1		

Variable	n (col %)	No delay	Doctor delay (row %)	OR	95% CI	p-value*
Yes	219 (85.5)	90	129 (58.9)	1.69	0.84 - 3.39	0.14
Type of house						
'Village'	204 (78.4)	87	117 (57.3)	1		
Residential	28 (10.8)	10	18 (64.3)	1.34	0.59 - 3.04	
Others	28 (10.8)	14	14 (50)	0.74	0.34 - 1.64	0.56
Alcohol intake (n_{miss}=1)						
Never	93 (35.8)	45	48 (51.6)	1		
Past intake	133 (51.1)	51	82 (61.6)	1.51	0.88 - 2.58	
Current	34 (13.1)	15	19 (55.9)	1.19	0.54 - 2.61	0.32
History of smoking (n_{miss}=1)						
Never	109 (41.9)	46	63 (57.8)	1		
Ex-smoker	116 (44.6)	50	66 (56.9)	0.96	0.57 - 1.63	
Current	35 (13.5)	15	20 (57.1)	0.97	0.45 - 2.10	0.99
Past history of drug abuse						
No	243 (93.5)	105	138 (56.8)	1		
Yes	17 (6.5)	6	11 (64.7)	1.39	0.50 - 3.90	0.52

* p-value from likelihood ratio test

b. Medical and family history

There is weak evidence to suggest that those with co-morbidity were more likely to have doctor delay (OR: 1.58, CI: 0.92 - 2.71). (Table 8.4)

Table 8.4: Univariate analysis of medical and family history factors (intermediate determinants) and doctor delay

Variable	n (%)	No delay	Doctor delay (row %)	OR	95% CI	p-value*
Problem with mobility						
No	228 (87.7)	98	130 (57)	1		
Yes	32 (18.3)	13	19 (59.4)	1.10	0.52 - 2.34	0.80
Co-morbidity						
No	175 (67.3)	81	94 (53.7)	1		
Yes	85 (32.7)	30	55 (64.7)	1.58	0.92 - 2.71	0.09
Family history of TB (n_{miss}=1)						
No	126 (48.6)	59	67 (53.2)	1		
Yes	133 (51.4)	52	81 (60.9)	1.37	0.83 - 2.25	0.21

* p-value from likelihood ratio test

c. Symptoms

Those with chest pain, loss of weight and fever had more than double the odds of doctor delay. (Table 8.5)

Table 8.5: Univariate analysis of symptoms experienced by respondents (proximal determinants) and doctor delay

Variable	n (col %)	No delay	Doctor delay (row %)	OR	95% CI	p-value*
Cough						
No	21 (8.1)	8	13 (61.9)	1		
Yes	239 (91.9)	103	136 (56.9)	0.81	0.32 - 2.04	0.66
Chest pain						
No	123 (47.3)	65	58 (47.2)	1		
Yes	137 (52.7)	46	91 (66.4)	2.22	1.33 - 3.70	0.002
Shortness of breath						
No	96 (36.9)	45	51 (53.1)	1		
Yes	164 (63.1)	66	98 (59.8)	1.31	0.79 - 2.18	0.30
Hemoptysis						
No	132 (50.8)	53	79 (59.9)	1		
Yes	128 (49.2)	58	70 (54.7)	0.81	0.49 - 1.33	0.40
Loss of appetite						
No	76 (29.2)	36	40 (52.6)	1		
Yes	184 (70.8)	75	109 (59.2)	1.31	0.76 - 2.24	0.33
Loss of weight						
No	36 (13.8)	23	13 (36.1)	1		
Yes	224 (86.2)	88	136 (60.7)	2.73	1.30 - 5.75	0.006
Insomnia						
No	88 (33.8)	38	50 (56.8)	1		
Yes	172 (66.2)	73	99 (57.6)	1.03	0.61 - 1.73	0.91
Fever						
No	59 (22.7)	34	25 (42.4)	1		
Yes	201 (77.3)	77	124 (61.7)	2.19	1.20 - 3.99	0.009
Lethargy						
No	50 (19.2)	25	25 (50)	1		
Yes	210 (80.8)	86	124 (59.1)	1.44	0.77 - 2.68	0.25

* p-value from likelihood ratio test

d. Health care utilisation

Those who have used government health facilities were less likely to have doctor delay. Those who had to travel longer than 30 minutes to the nearest clinic were less likely to have doctor delay. However, there was no trend across the travel time to the nearest clinic. For the current illness (TB), those who went to other provider other than government clinic were twice as likely to have doctor delay. Those who walked to the treatment choice for current

illness (TB) had thrice the odds of doctor delay compared to those who used public transport. (Table 8.6)

Table 8.6: Univariate analysis of health care utilisation factors (intermediate determinants) and doctor delay

Variable	n (col %)	No delay	Doctor Delay (row %)	OR	95% CI	p-value*
Ever use government health facility						
Yes	220 (84.6)	100	120 (54.6)	1		
No	40 (15.4)	11	29 (72.5)	2.19	1.04 - 4.61	0.04
Number of times used over past year (n_{miss}=3)						
Never use	40 (15.6)	11	29 (72.5)	1		
None	50 (19.5)	21	29 (58)	0.52	0.21 - 1.28	
1 - 2 times	61 (23.7)	32	29 (47.5)	0.34	0.15 - 0.81	
3 or more	106 (41.2)	46	60 (56.6)	0.49	0.22- 1.09	0.09
Travel time to the nearest clinic (n_{miss}=2)						
< 15 min	140 (54.2)	57	83 (59.3)	1		
15 - 29 min	83 (32.2)	32	51 (61.5)	1.09	0.63 - 1.91	
≥ 30 min	35 (13.6)	21	14 ()	0.46	0.22 - 0.97	0.08
Transport to the nearest clinic						
Public transport	116 (44.6)	53	63(54.3)	1		
Own transport	96(36.9)	37	59 (61.5)	1.34	0.77 - 2.32	
Walk	48(18.5)	21	27 (56.3)	1.08	0.55 - 2.13	0.57
Travel time to the nearest hospital (n_{miss}=1)						
< 15 min	46 (17.8)	25	21 (45.7)	1		
15 - 29 min	94 (36.3)	34	60 (63.8)	2.10	1.03 - 4.30	
≥ 30 min	119 (45.9)	51	68 (57.1)	1.59	0.80 - 3.15	0.12
Transport to the nearest hospital						
Public transport	157 (60.4)	72	85 (54.1)	1		
Own transport	97 (37.3)	37	60 (61.9)	1.37	0.82 - 2.30	
Walk	6 (2.3)	2	4 (66.7)	1.69	0.30 - 9.52	0.43
Usual first choice of treatment (n_{miss}=1)						
Gov clinic	189 (73)	84	105 (55.6)	1		
Others	70 (27)	26	44 (62.9)	1.35	0.77 - 2.38	0.29
Treatment choice for current illness (TB)						

Variable	n (col %)	No delay	Doctor Delay (row %)	OR	95% CI	p-value*
Gov clinic	189 (72.7)	89	100 (52.9)	1		
Others	71 (27.3)	22	49 (69)	1.98	1.10 - 3.56	0.02
Travel time to treatment choice						
< 15 min	94 (36.1)	39	55 (58.5)	1		
15 - 29 min	88 (33.9)	33	55 (62.5)	1.18	0.65 - 2.14	
≥ 30 min	78 (30)	39	39 (50)	0.71	0.39 - 1.30	0.26
Transport to the treatment choice for current illness (TB)						
Public transport	128 (49.2)	63	65 (50.8)	1		
Own transport	107(41.2)	42	65 (60.8)	1.5	0.89 - 2.52	
Walk	25(9.6)	6	19 (76)	3.07	1.15 - 8.19	0.04

* p-value from likelihood ratio test

e. Health provider factors

At the first attendance to the government clinic (including those who had first seen private doctors), those who had sputum examination were less likely to have doctor delay compared to those who did not. (Table 8.7) A repeat visit to the first provider resulted in over 4 times the odds of doctor delay compared with those respondents who did not have repeat visit. Those who were satisfied with the services provided were less likely to have doctor delay.

Table 8.7: Univariate analysis of health provider factors (proximal determinants) and doctor delay

Variable	n (col %)	No delay	Doctor delay (row %)	OR	95% CI	p-value*
Sputum exam at 1st visit to government clinic						
Yes	181 (69.6)	91	90 (49.7)	1		
No	79 (30.4)	20	59 (74.7)	2.98	1.66 - 5.35	<0.001
Repeat visit to first provider						
No	169 (65)	92	77 (45.6)	1		
Yes	91 (35)	19	72 (79.1)	4.53	2.43 - 8.45	<0.001
Referral made by first provider						
No	233 (89.6)	98	135 (57.9)	1		
Yes	27 (10.4)	13	14 (51.9)	0.78	0.35 - 1.74	0.55

Hospitalised						
No	200 (76.9)	83	117 (58.5)	1		
Yes	60 (23.1)	28	32 (53.3)	0.87	0.44 - 1.72	0.68

* p-value from likelihood ratio test

8.4.2 Multivariate analysis of doctor delay of more than 14 days

As with patient delay, all the variables in the univariate analysis with p-values ≤ 0.2 and all those identified as *a priori* confounders were considered in the multivariate analysis. Several variables were at the distal level: sex, age group, education level, household income, owned transport, land and has TV or radio. Seven variables were at the intermediate level: co-morbidity, ever use government facility, number of times used government facility in past year, travelling time to nearest clinic, travelling time to nearest hospital, treatment choice for current illness (TB) and mode of transport to treatment choice for current illness (TB). Sputum examination at first visit to government clinic, repeat visit to first provider, chest pain, loss of weight and fever were at the proximal level. As before, sex and age group were *a priori* confounders and retained in all the models while education level and household income were included because they were considered potential confounders.

Among the intermediate determinants, there were two variables; travelling times to the nearest health facility (clinic and hospital) that satisfied the criteria for consideration in the multivariate model. As almost all diagnosis could be made at the clinic level, only the travelling time to the nearest clinic was considered in the multivariate analysis.

a. Multivariate analysis with distal determinants - multivariate modelling stage 1

Education level and household income were included as they were potential confounders. Two variables at the distal level were not retained: owned land and own TV or radio as they did not attained the p-value of ≤ 0.1.

Table 8.8: Multivariate analysis of distal determinants for doctor delay (n=252)

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value*
Sex					
Male	1		1		
Female	1.24	0.74 - 2.08	1.60	0.90 - 2.85	0.11
Age group (years)					
18 - 29	1		1		
30 - 39	1.39	0.67 - 2.85	1.27	0.59 - 2.74	
40 - 49	1.45	0.72 - 2.95	1.81	0.82 - 4.00	
50 - 59	0.98	0.45 - 2.14	1.39	0.55 - 3.52	
60 - 88	1.67	0.77 - 3.61	3.88	1.36 - 11.04	0.10
Education					
None	1		1		
Primary	1.27	0.64 - 2.52	2.40	1.02 - 5.60	
Secondary & above	1.38	0.71 - 2.66	3.44	1.30 - 9.11	0.04**
Household income					
No fixed income	1		1		
< USD 132	0.77	0.24 - 2.48	0.53	0.14 - 1.97	
≥ USD 132	0.63	0.20 - 1.92	0.33	0.09 - 1.21	0.12#
Own transport					
No	1		1		
Yes	1.87	1.10 - 3.18	2.02	1.11 - 3.66	0.02

* p-value from likelihood ratio test
** p-value for trend of odds=0.39
# p-value for trend of odds=0.83

b. Multivariate analysis with distal and intermediate determinants - stage 2

The variable 'ever use government facility' showed high collinearity with 'number use of government facility over past year' and so the latter was not retained in subsequent model. The variable 'co-morbidity' was also not included in the model because of its p-value of 0.28.

Table 8.9: Multivariate analysis of distal and intermediate determinants for doctor delay (n=250)

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value*
Sex					
Male	1		1		
Female	1.24	0.74 - 2.08	1.78	0.98 - 3.25	0.06
Age group (years)					
18 - 29	1		1		

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value*
30 - 39	1.39	0.67 - 2.85	1.17	0.52 - 2.63	
40 - 49	1.45	0.72 - 2.95	1.83	0.80 - 4.16	
50 - 59	0.98	0.45 - 2.14	1.46	0.55 - 3.90	
60 - 88	1.67	0.77 - 3.61	3.82	1.29 - 11.34	0.14
Education					
None	1		1		
Primary	1.27	0.64 - 2.52	2.14	0.90 - 5.12	
Secondary & above	1.38	0.71 - 2.66	2.97	1.09 - 8.09	0.09
Household income					
No fixed income	1		1		
< USD 132	0.77	0.24 - 2.48	0.63	0.16 - 2.43	
≥ USD 132	0.63	0.20 - 1.92	0.26	0.07 - 0.98	0.01
Own transport					
No	1		1		
Yes	1.87	1.10 - 3.18	1.98	1.06 - 3.69	0.03
Ever use government health facility					
Yes	1		1		
No	2.19	1.04 - 4.61	2.37	0.99 - 5.68	0.05
Travel time to the nearest clinic					
< 15 min	1		1		
15 - 29 min	1.09	0.63 - 1.91	1.13	0.60 - 2.15	
≥ 30 min	0.46	0.22 - 0.97	0.42	0.17 - 1.03	0.09
Treatment choice for current illness (TB)					
Gov clinic	1		1		
Others	1.98	1.10 - 3.56	1.78	0.90 - 3.50	0.09

* p-value from likelihood ratio test

c. Multivariate analysis with distal, intermediate and proximal determinants - stage 3

In the final model, having sputum examination at the first visit to the government clinic was retained despite a p-value exceeding 0.1 as it decreases the odds ratio for repeat visit by more than 20%. The variable 'fever' was not retained due to its p-value of 0.15.

After adjusting for distal, intermediate and confounding factors, those educated, those who had never used government facility, had chest pain and loss of weight were twice more likely to be associated with doctor delay. (Table 8.10) A repeat visit to the first provider resulted in approximately 4 times doctor delay than those who did not (AOR: 3.88, CI: 1.79 - 8.39). Those who chose non-government clinic for current illness (TB) had almost twice the odds of having doctor delay. Those who had sputum examination done at the first visit to government facility were 1.6 times more likely to have doctor delay. In contrast, those with household income of ≥ USD 132 were less likely to have doctor delay.

Table 8.10: Multivariate analysis of distal, intermediate and proximal determinants for doctor delay (n=250)

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value*
Sex					
Male	1		1		
Female	1.24	0.74 - 2.08	1.36	0.70 - 2.64	0.37
Age group (years)					
18 - 29	1		1		
30 - 39	1.39	0.67 - 2.85	1.12	0.47 - 2.71	
40 - 49	1.45	0.72 - 2.95	1.88	0.74 - 4.81	
50 - 59	0.98	0.45 - 2.14	1.05	0.33 - 3.29	
60 - 88	1.67	0.77 - 3.61	2.83	0.83 - 9.66	0.32
Education					
None	1		1		
Primary	1.27	0.64 - 2.52	2.00	0.73 - 5.46	
Secondary & above	1.38	0.71 - 2.66	2.69	0.85 - 8.54	0.36
Household income					
No fixed income	1		1		
< USD 132	0.77	0.24 - 2.48	0.51	0.10 - 2.49	
≥ USD 132	0.63	0.20 - 1.92	0.20	0.04 - 0.96	0.02
Own transport					
No	1		1		
Yes	1.87	1.10 - 3.18	1.47	0.73 - 2.92	0.28
Ever use government health facility					
Yes	1		1		
No	2.19	1.04 - 4.61	2.70	1.04 - 6.98	0.04
Travel time to the nearest clinic					
< 15 min	1		1		

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value*
15 - 29 min	1.09	0.63 - 1.91	1.20	0.60 - 2.40	
≥ 30 min	0.46	0.22 - 0.97	0.41	0.15 - 1.13	0.11
Treatment choice for current illness (TB)					
Gov clinic	1		1		
Others	1.98	1.10 - 3.56	1.85	0.89 - 3.87	0.10
Repeat visit					
No	1		1		
Yes	4.53	2.43 - 8.45	3.88	1.79 - 8.39	0.001
Sputum exam at 1st visit					
Yes	1		1		
No	2.98	1.66 - 5.35	1.66	0.76 - 3.62	0.20
Chest pain					
No	1		1		
Yes	2.22	1.33 - 3.70	2.71	1.45 - 5.08	0.002
Loss of weight					
No	1		1		
Yes	2.73	1.30 - 5.75	2.26	0.93 - 5.47	0.04

* p-value from likelihood ratio test

8.4.3 Analysis of doctor delay of more than 60 days

The secondary outcome for doctor delay uses a different cut-off point of 60 days. Of the 260 respondents, 24.2% (95% CI: 19 - 29.5) had doctor delay of more than 60 days.

a. Univariate analysis

As with doctor delay of more than 14 days, socio-demographic variables were compatible with no association with doctor delay of greater than 60 days. Similarly, medical, family and social history factors were also compatible with no association with doctor delay.

However, those with shortness of breath and fever tended to have doctor delay of more than 60 days; OR: 2.49(CI: 1.28-4.87, p-value=0.006) and OR: 2.87 (CI: 1.21 - 6.78, p-value=0.01) respectively. Also, those who had used government health facilities in the past were less likely to have doctor delay of more than 60 days (OR: 0.46, CI: 0.22 - 0.96, p-value=0.03). Choosing a non-government health facility for current illness (TB) was associated with

doctor delay of more than 60 days compared to those who chose government clinics.

Those who did not have sputum examination done at the first visit to a government clinic had double the odds for doctor delay of more than 60 days than those who had sputum examination done. In addition, a repeat visit to the first provider resulted in approximately 4 times doctor delay of more than 60 days. The detailed results for these univariate analyses are available in Appendix 9.

b. Multivariate analysis for doctor delay of more than 60 days

The variables listed below were included in the model for the multivariate analysis. At the distal level were sex, age group, education level and household income while ever use government facility, number of times used government facility in the past year and treatment choice for current illness (TB) were at the intermediate level. The variables at the proximal level were sputum exam at first visit to government facility, repeat visit to first provider, chest pain, and shortness of breath, loss of weight, fever and lethargy. The process for inclusion followed previous steps already described.

Table 8.11 shows the findings from multivariate analysis. After controlling for the effects of confounding and other variables, those who have never use government health facility were twice more likely to have doctor delay of more than 60 days compare to those who had (CI: 0.87 - 5.51). A repeat visit to the first health provider resulted in 6 times the odds of doctor delay of greater than 60 days. Those with fever had almost thrice the odds for doctor delay of more than 60 days (AOR: 2.98, CI: 1.13 - 7.83). Those with primary education, had chest pain and shortness of breath were approximately 1.7 times more likely to have doctor delay of greater than 60 days that those who did not. Those with household income were less likely to have doctor delay of more than 60 days than those without income.

Table 8.11: Multivariate analysis of distal, intermediate and proximal determinants for doctor delay of more than 60 days (n=252)

Variable	Univariate analysis		Multivariate analysis		
	Unadjusted OR	95% CI	Adjusted OR	95% CI	p-value*
Sex					
Male	1		1		
Female	0.93	0.51 - 1.69	0.77	0.37 - 1.61	0.49
Age group (years)					
18 - 29	1		1		
30 - 39	1.00	0.44 - 2.25	0.95	0.37 - 2.43	
40 - 49	0.90	0.40 - 2.02	0.85	0.30 - 2.38	
50 - 59	0.92	0.37 - 2.27	0.63	0.18 - 2.18	
60 - 88	0.67	0.27 - 1.69	0.43	0.10 - 1.79	0.81
Education					
None	1		1		
Primary	1.27	0.64 - 2.52	1.77	0.57 - 5.47	
Secondary & above	1.38	0.71 - 2.66	1.20	0.32 - 4.45	0.44
Household income					
No fixed income	1		1		
< USD 132	0.77	0.24 - 2.48	0.24	0.06 - 1.03	
≥ USD 132	0.63	0.20 - 1.92	0.22	0.05 - 0.90	0.11
Ever use government health facility					
Yes	1		1		
No	2.15	1.05 - 4.40	2.19	0.87 - 5.51	0.09
Treatment choice for current illness (TB)					
Gov clinic	1		1		
Others	1.98	1.10 - 3.56	1.54	0.68 - 3.46	0.30
Sputum exam at 1st visit					
Yes	1		1		
No	2.29	1.27 - 4.13	0.93	0.40 - 2.17	0.87
Repeat visit					
No	1		1		
Yes	4.13	2.21 - 7.71	6.04	2.61 - 14.00	<0.001
Chest pain					
No	1		1		
Yes	2.22	1.33 - 3.70	1.73	0.84 - 3.57	0.13
Shortness of breath					
No	1		1		
Yes	1.31	0.79 - 2.18	1.74	0.82 - 3.69	0.15
Fever					
No	1		1		
Yes	2.19	1.20 - 3.99	2.98	1.13 - 7.83	0.03

* p-value from likelihood ratio test

The above completes the multivariate analysis of doctor delay and the discussion for the results is presented in the next chapter.

9 CHAPTER 9: Discussion

This chapter discusses the findings of the quantitative study and the strength and limitations of the study, makes relevant comparisons with other studies, and suggests how the findings contribute to current knowledge and makes suggestions on how it could be improved and finally recommendations for future studies.

9.1 Summary of findings

The findings from this study revealed that only the usual first choice for treatment was associated with patient delay of more than 30 days. Patients whose usual first place for treatment was non-government health facilities had more than double the odds of patient delay than those whose first choice was government clinics. In addition, those aged between 30 to 39 years old were 2.6 times more likely to have patient delay compared to the baseline group of 18 to 29 years old. Those who lived in 'other' type of house (not 'village' and not residential) were less likely to have patient delay compared to those who lived in 'village' houses but not in those living in residential housing. No important association was seen in this dataset with education level or with female sex.

For patient delay of more than 90 days, similar finding to the above was noted. Those who usually sought treatment at non-government facilities were 2.3 times more likely to have patient delay of more than 90 days compare to those who usually preferred government clinics. Similarly, those aged 30 to 39 years also had double the odds of patient delay of more than 90 days compared to the baseline age group of 18 - 29 years old. There was weak evidence that those who owned livestock and had other medical conditions were also almost twice more likely to have patient delay of more than 90 days. Again, it was found that gender and education level were compatible with no association with 'extreme' patient delay.

For doctor delay of more than 14 days, those educated, those who had never used government facility, had chest pain and loss of weight were twice more likely to be associated with doctor delay. A repeat visit to the first provider resulted in approximately 4 times doctor delay than those who did not. Those who chose non-government clinic for current illness (TB) had almost twice the odds of having doctor delay. Those who had sputum examination done at the first visit to government facility were 1.6 times more likely to have doctor delay. In contrast, those with household income of ≥ USD 132 were less likely to have doctor delay.

For 'extreme' doctor delay (more than 60 days), those who have never use government health facility were twice more likely to have doctor delay of more than 60 days compare to those who had. A repeat visit to the first health provider resulted in 6 times the odds of 'extreme' doctor delay while those with fever had almost thrice the odds. Those with primary education, had chest pain and shortness of breath were approximately 1.7 times more likely to have doctor delay of greater than 60 days that those who did not. Those household with income were less likely to have doctor delay of more than 60 days than those without income.

9.2 Strengths of the study

The strength of this study is in making available a wealth of relevant data on factors affecting case finding for TB such as socio-demographic, health care utilisation and symptomatology following a relatively short period of research work. These data were useful in generating information on important elements of TB control efforts such as the journey or time period from illness to treatment. Such information on time periods was not available prior to this study.

Despite this being a cross sectional study, the coverage was fairly broad as it covered 10 out of the 23 districts in Sabah. In addition, it covered most of the ethnic groups in Sabah and also urban and rural areas. The sample size was estimated based on previous study done in Penang, West Malaysia where the

sample size in that study was only 100. This sample size is comparable to many studies such as in the Philippines study (302 patients)[84], Italian study (271)[77], South Africa study (298)[63], Tanzanian study (296)[73] and California study (248)[30]. The smallest sample size was the Teheran study (50 patients)[67] and the most was the Spain study (7037 patients)[62].

The analysis in this Sabah study was also rigorous especially in the multivariate analysis using a very detailed conceptual framework for analysis and in using 2 different cut-off points for both patient and doctor delay. Of the 38 studies in 29 countries reviewed, only five studies reported on results of multivariate analysis after control of confounding factors.

The use of both qualitative and quantitative approaches proved invaluable in this research. The qualitative study provided information about health and health care seeking behaviour among TB patients and in the community. Such information was also valuable in informing the questionnaire development such that the questionnaire became relevant to the setting.

9.3 Limitations of the study

9.3.1 Generalisability

The study was conducted in 10 out of 23 districts in Sabah and the sample was drawn from the TB Treatment Registry at the health centre. As TB is a notifiable disease under Act 342 and based on past knowledge, almost all TB patients received their treatment at government facilities, it is likely that the study had good representation of all PTB patients in the 10 districts.

Although the study involved as many different races as possible, its confinement to the west coast made it not generalisable to the whole population of Sabah. There are many ethnic groups residing in the east coast which were not represented in the sample. As mentioned in 5.2.2, the immigrant populations were excluded due to their mobility and the tight research schedule. However, it is postulated that for various social reasons

such as mobility and fear of authority due to their illegal status they would have different health and health care seeking behaviours such as that found among immigrants in the California study[30].

9.3.2 Selection bias

There is bias due to the fact that the participants were patients who seek treatment at the health facilities including private clinics and ended up being diagnosed at government health facilities. There may be others who sought treatment elsewhere and never use the government or private health facilities. There is no way one can find out the reason why and when they seek treatment unless one does a community survey. In addition, patients with TB symptoms who died before being diagnosed were also excluded from the study.

Selection bias was minimised by ensuring that sufficient attempts were made to interview all eligible respondents. Comparison between those consented and those not consented (due to death, refusal and not contactable) did not reveal any difference for gender and age and thus, a condition known as volunteer bias[128] may not be a major issue.

9.3.3 Information bias

Information bias occurred when determining the time period and delay and inlcude recall bias, interviewer bias and missing data.

a. Calculation of time period and delay

There were many difficulties in ascertaining past symptoms and onset of these symptoms by participant self-report. This has not been revealed in great details by those who have embarked on such research. Attempts to use similar approaches used by other studies such as by improving recall in relation to local events[69] did not prove successful in the context of Sabah. Although triangulation methods such as the use of clinical records, interviews with carers or close contacts may be useful, it does leave one with the dilemma of choosing a single date in the presence of discrepancies between reports. In

Sabah, once a patient is diagnosed, a clinical record of the current illness (TB) is created for the patient but information on the duration of illness or date of start of illness was not systematically recorded. They are kept in the Chest clinic for several years. The reason for this is because even after completing treatment, the patients are still reviewed on a regular basis for a period of 18 months. The case notes for TB suspects prior to TB diagnosis are kept in the Out-Patient Department (OPD) of the clinics. Due to the difficulties in getting the OPD notes and the potential inconsistencies and incomplete information on symptoms and their durations, participant self-report for the date of onset, duration of symptoms and the date of seeking treatment was used. The date of starting treatment was the only date obtained from patients' clinical records.

In the calculation of patient time period, date of first seeking treatment was used together with the maximum duration of the four symptoms (cough, hemoptysis, fever and loss of weight) to generate a date for the onset of symptoms. This is a departure from what other researchers have done such as Pronyk et al[63] and Salaniponi et al[129] who both used one symptom (cough).

In the calculation of the doctor time period, the interval started from the date the patient consulted a medical practitioner in either government or private clinics. This is because all doctors even those in private practice should be able to diagnose TB clinically and managed accordingly.

Errors in obtaining a correct time period are likely to have occurred in the following ways.

a. Problems with recall may provide an inaccurate date for date of seeking treatment or for duration of symptoms.
b. In cases, where respondents tried their best to provide a date or duration of symptoms, they often 'round' up the numbers such as '30 days' or 'about a year' which was reflected in clustering around certain values on the graph on time period.

c. In the approximation of the term 'early', 'middle' and 'end', assigning a fixed number also contributed to inaccuracies of the time period.

It is therefore relevant to interpret the findings on time period and delay in view of these errors. In addition, it is just as important to identify such errors in order that steps could be undertaken to minimise such errors in future researches.

b. Recall bias

Another factor related to recall bias is one's ability to recognise symptoms as the expression of an illness. Patients may be more aware of a symptom when it became worse, persistent or affected their daily activities. In terms of seeking care, that may be sufficient but in the wider perspective of limiting transmission, inability to recognise the symptom is a public health problem.

In addition, there was a delay from starting treatment and being interviewed; almost two fifths were interviewed within 30 days of starting treatment. This time lapse may have also contributed to recall bias. On the other hand, when a patient has just been diagnosed and started on treatment, it may not be beneficial to interview them on the same day. This study also noted that TB patients went through considerable psycho-social and physical stress which may be more disturbing at the early stage of the disease and when interviewed too early might also affect the ability to recall events.

There was also potential for differential bias if the ability to recall dates differed between age, gender and ethnic groups and even between certain such groups such as smokers. This may have been contributed to different interpretation of symptoms. For example, smokers may interpret early symptoms of cough as being due to smoking rather than the onset of TB or patients with co-morbidity may regard earlier symptoms of loss of weight as due to pre-existing illness.

c. Interviewer bias

All three RAs were sufficiently trained to conduct the interview in Bahasa Malaysia using similar approach and terminologies. Although, Bahasa Malaysia is the national language, it is often not the first language among Sabahans. When they do use Bahasa Malaysia, they speak in a variant of this language. Therefore, due to some diversity in dialects, there may be some misclassifications of the explanatory variables.

d. Missing data

The study also revealed the need to improve on the complete documentation of the results in the patients' case notes. Although the sputum examination and chest x-ray results were not used in relation to the outcome measurement, missing data in both these areas limited their use in the descriptive analysis. In almost half the cases, the results of some of the sputum examination were not in the notes and when they were in the notes, often the dates on which the reading was made were missing. All respondents have their chest x-rays in the case notes but in almost half of them, their results were missing. Missing data from questionnaires were very few and most missing data were with reference to date of seeking treatment or duration of symptoms.

9.3.4 Other limitations

The calculated sample size of 386 was based on the previous study in West Malaysia[58]. The percentage of patient delay among those with secondary education was much higher (53%) than that used in the estimation (30%) and a recalculation of required sample size based on this percentage revealed that the current sample size was sufficient to detect an odds ratio for delay exceeding 2.0 based on a type I error of 5% and 80% power.

The other limiting factor is that this was a cross sectional study which may make it difficult to assess a clear cause and effect relationship. For example, in this study it was revealed that the explanatory factor for patient delay was because the patients sought non-government health services but it is possible that individuals may have been embarrassed at the long time they had taken before attending and preferred the private services for perceived greater

confidentiality. However, why delay occurs among such group could not be explained from this study. One can expand the research by doing further exploratory work on those who delayed by comparing between those who attended government health facilities and those who sought non-government practitioners.

9.4 Comparison to other studies

Comparison of explanatory factors identified from other studies is difficult for several reasons:

a. differences in health and health care seeking behaviour of the study population
b. differences in health care system and setting
c. differences in definition of time period and the use of either median or mean. Comparison in this chapter is made with studies with similar definitions and where the median was used.
d. the use of different cut-off point for delay
e. the rigor of analysis

In identifying the explanatory factors for delay in the chapter on literature review, all studies regardless of whether median or mean was used were reviewed. Differences in health and health care seeking behaviour meant that a variety of health care providers may have been consulted for diagnosis and treatment and delay could arise from these practices including the capacity and ability of the providers to make an accurate diagnosis and start treatment promptly. For example, in the Gambia, some patients may prefer to consult non-governmental clinics but need to be referred to the National TB Control Programme as anti-TB drugs are not available in any pharmacies in that country and thus limits the ability of private doctors to start treatment.[69] Therefore, the explanatory factors for delay in the Gambian study would differ with the Sabah study as in Sabah, almost all clinics in the government and private sectors can provide treatment.

The definitions of time period are also influence by the availability of different providers and also the health care setting in the study area. For

example, when a patient can only access modern medicine through a particular clinic, to be referred to another for diagnostic procedures and again referred to another for treatment, then a study on delay should take into consideration the different time period and delay at all stages. In the Lagos study, doctor delay refers to the time period from the first consultation with any health provider (including non medical provider) to being seen at the Chest Clinic at the General Hospital. Treatment delay is defined as the time from being seen at the Chest Clinic and commencement of treatment.[68] Therefore, in terms of comparison there are several issues to be addressed. Firstly, not all health facilities in Lagos could diagnose TB whereas in Sabah, almost all health facilities besides those run by midwives could diagnose TB. Secondly, doctor time period in the Lagos study refer to the period between referral to the Chest Clinic where as in this Sabah study, it included what was termed as 'treatment delay' in the Lagos study. The situation in Lagos is similar to that in Zambia and UK where diagnosis and treatment are provided at a referral Chest Clinic[26, 60] or at government hospitals in Malawi[129]. In the South Africa study, the end-point used was 'hospitalisation' which was routinely done upon diagnosis. In these studies, a prolonged time period is not surprising for those who sought treatment at GP or health clinics compared to those whose first contacts were with the hospitals.[63]

In addition, calculation of time period can be as straightforward as extracting the date of symptom onset and first medical consultation from the case notes or through interviews as was done by most studies. Even this can differ in the symptoms chosen; some studies chose cough as the presenting symptom while others used all the other symptoms suggestive of TB. Calculation can also be done by averaging the time periods collected from different sources as done by Paynter et al.[60] In this Sabah study, the maximum duration of four symptoms (cough, hemoptysis, fever and loss of weight) was used in the calculation of patient time period. These differences in estimation may result in limitations in comparing studies.

Differentiation between patient and doctor or health care system time period may also be an issue. For example, when patient has to wait to obtain an appointment with a health care provider, it should be considered as contributing to the health provider time period and not patient time period. However, by using 'consultation with medical provider' as the beginning point for doctor time period, this waiting period for appointment is included in the patient time period. In addition, the use of a different cut-off point for delay may also revealed different explanatory factors as demonstrated in this study by the usage of 14 and 60 days for doctor delay.

The rigor of analysis also affects the findings especially when comparing explanatory variables for delay. Some studies are descriptive in content.[67, 73, 129] In some, only univariate analysis was done[26, 30, 60, 66, 68] and only in a few that multivariate analysis was performed[30, 62-65]. Therefore, comparison of explanatory factors needs to be discussed against such analytical frameworks. In spite of all the differences, relevant comparisons in terms of median and delay are made in the following paragraphs.

9.4.1 Comparison of patient time period with the literature

In this study, the percentage of patients who sought treatment after 30 days was 51.8% (95% CI: 45.9 - 57.8). In the West Malaysia (Penang) study, the percentage was lower at 34%[58]. Other studies have also shown lower percentages; Teheran (12%)[67], Ethiopia (41%)[66], Spain (43%)[62]. The study conducted in the Philippines showed a similar percentage (50%)[84] and two studies showed higher percentages of 83% in Lagos, Nigeria[68] and 85% in Tanzania[73]. The percentage in Zambia was lower at 35% [18]. This study was carried out among adults presenting with cough in only 2 health centres in Lusaka.

The median patient time period of 60 days (8.6 weeks) is similar to the Ethiopian study[66], Lusaka, Zambia[26] and Nigeria[68], longer than the reported median of 2 weeks in the West Malaysia studies [57, 58] and in that seen in other studies such as Spain (22 days)[62], New York (25 days)[64],

Botswana (3 weeks)[65], Queensland (30 days)[70], South Africa (4 weeks)[63] and UK (34.5 days)[60] but shorter than in Tanzanian study (120 days)[73].

9.4.2 Explanatory factors associated with patient delay

In a multivariate analysis after appropriate adjustment of confounders in a multivariate analysis, those whose usual first treatment choice was a non-government health facility were twice more likely to have patient delay than those whose usual first choice was a government facility (Adjusted OR: 2.28, CI: 1.03 - 5.06). This is similar to findings from other studies which compared non-governmental facilities such as traditional healers and private clinics to government facilities for patient delay. Among smear positive PTB patients who sought folk therapy in rural Hunan, China[83], patients with cough who had prior attendance at private clinics in Lusaka, Zambia[18] and PTB patients in Mwanza, Tanzania[73] who sought treatment from traditional healers, all revealed patient delay compared with those who sought governmental providers. This is in contrast to TB patients in South India where those who initially consulted a government provider were twice more likely to have patient delay than those who sought private clinics.[71]

As mentioned in 1.2, patient time period reflects the health and health care seeking behaviour of an individual. In the Mwanza study, it is understandable that one who sought traditional medicine would have longer patient delay as the definition of patient delay is from onset to first medical consultation at the health facility.[73] However, when patient delay involves private clinics such as in the Sabah study and as seen in the study in Lusaka[18] or government clinics in South India[71], the reasons for the delay are harder to explain. In Sabah, as mentioned in 6.4.1, those with higher income preferred private practitioners. It may also be that this group did not perceive their symptoms as serious enough to seek treatment or that they were too busy with their work to be bothered with the symptoms.

In the Sabah study, those who lived in 'other' type of house (not 'village' and not residential) were less likely to have patient delay compared to those who lived in 'village' houses (AOR: 0.27, CI: 0.11 - 0.71) but not in those living in

residential housing. It should be pointed out that 'others' include a 'mixed' group in terms of socio-demographic characteristics and not just the type of houses. Almost two thirds of this group preferred government facility and almost 83% earned more than USD132 per month. In comparison, although almost 75% of those living in 'village' houses also preferred government facilities but around half earned less than USD132 per month and thus may have financial problems in terms of getting treatment such as transportation cost. As such, the former group may have no problem in accessing health services in particular government health facilities. No other studies have reported a similar finding.

In addition to the cut-off point of 30 days, another cut-off point of 90 days was used to analyse the group with 'extreme' patient delay which constituted a quarter of the respondents. The reason for analysing those with 'extreme' delay is to identify whether the explanatory factors are different in those who may be more infectious and who could be considered for targeting when resources are scarce.

In the multivariate analysis for patient delay of more than 90 days, the usual first place for seeking treatment was associated with patient delay. Those who usually sought treatment at non-government facilities were 2.3 times more likely to have patient delay of more than 90 days compare to those who usually prefer government clinics (AOR: 2.28, CI: 1.11 - 4.68). This finding is similar to patient delay of 30 days.

Those who owned livestock and had co-morbidity were also almost twice more likely to have patient delay of more than 90 days (AOR: 1.88, CI: 0.98 - 3.63 and AOR: 1.95, CI: 0.97 - 3.91). It is difficult to explain why someone who owned livestock would have a patient delay of more than 90 days. One can again speculate only that difficulty in leaving land and animals may be factors leading to delay in health care seeking. However, evidence of the association is weak and may be due to chance.

Even in the univariate analysis, those with co-morbidity had double the odds of patient delay of more than 90 days (OR: 1.92, 95% CI: 1.07 - 3.44) compared to those without. This may be due to the perception that symptoms of TB as due to their medical conditions rather than a new disease. In addition, since they were already on regular follow-up, they might have waited until their review appointment to seek treatment for the symptoms.

All the following studies used median as a cut-off point to describe patient delay. Findings in the Lagos[68] and the Ethiopian[66] studies reported low or inadequate knowledge on TB were reasons for prolonged patient time period. Some patients thought that the symptoms were harmless and would improve or treated by themselves: 70% of the patients in the Ethiopian study[66], 20% in the California study[30] and more than half in the Philippines study[84]. Among adults with cough presenting to the health centres in Lusaka, Zambia, perception of the health services as being poor was a more important cause to delay compared with knowledge on TB.[18] Similar finding of perceived poor reputation of government the reason for seeking treatment at private clinics (although expensive) but resulted in patient delay was revealed in the Philippines study.[84] In addition, other reasons were the lack of information on the availability of free treatment[68], long distance to the nearest health facility[66] and lack of money[84].

In the Teheran study, the mean was used as cut-off point to describe delay. The mean patient delay was 12.5 days (± 7.5days) and the reasons given for their delays were underestimation of the seriousness of their symptoms, being too busy, poor access to health care (2%) and dependency on their husbands (for the women).[67] Despite such dependency on their husband, women were less likely to delay. The authors suggested that the women took their health more seriously and are prepared to consult early compared to men.[67]

There was little association of these factors with gender and ethnicity and patient delay in the Sabah study. In the Lusaka, Zambia study, women more often seek treatment late. The authors suggested that the heavy workload of

women in addition to their lack of education, mobility, independence and lack of financial resources may have contributed to women presenting later than men.[26] In the New York study, being in the 55-64 age group and spoke a primary language other than English were associated with longer patient delay; AOR: 10.6, CI:1.3 - 86.9 and AOR: 2.5, CI: 1.0 - 5.8 respectively. The delay among non-English speaking groups reflected the difficulty in negotiating the health care system. The authors suggested that the delay in the 55-64 age group may be due to low index of suspicions on the occurrence of TB among this group as the focus of 'Think TB' campaigns on TB-HIV gave more emphasis on the 25 - 44 age group.[64]

In the Sabah study, hemoptysis was not examined as a main determinant of presentation with TB because it was one of the four main symptoms for which the duration was used to determine the time taken to present to health services. However, given it was the main symptoms of only 12 patients, its importance was explored in the final model and found there was no association with time to presentation, unlike in the Ethiopian study which found that those with hemoptysis were more likely to have patient delay compared to those without. (OR:1.90, CI: 1.16 - 3.12).[66] The authors suggested that patients stayed home for a long time until they noticed an alarming symptom such as hemoptysis before seeking treatment.

Factors associated with long patient delay were also assessed to determine which different groups who could end up as long term sources of TB in the community. Almost a quarter of the respondents in this study sought treatment more than 90 days after onset of illness. This is comparable to the findings in Ethiopia[66] and the Philippines[84] where 21% and 20% respectively of the smear positive patients sought medical treatment after 90 days from onset of illness. In Spain, 13% sought treatment after 3 months[62] while in Botswana, this figure was lower at 10%[65]. A much larger percentage of around 74% of the patients in Tanzania were treated after 3 months from the onset of symptoms.[73]

The preference for treatment of first choice being private care was also found to be associated with patient delay of more than 90 days as with those who delayed more than 60 days. In contrast, other settings had other factors associated with prolonged patient delay. In Spain, patient delay of more than 57 days (75th percentile) was associated with age (greatest delay in the 35 -64 age group), presentation of constitutional symptoms, alcoholism and being female.[62] In addition, more women delay more than 57 days before seeking treatment. suggested that this may be due to several reasons which needed further studies; one of which is that more women in the study seemed to be more prone to have extra-pulmonary TB compared to men.[62]

9.4.3 Doctor time period and median for doctor delay

The median doctor time period for a total of 260 respondents was 20 days (IQR: 7 - 59 days, range 0 - 551 days). This is very different from the two studies in West Malaysia where the median doctor delay longer; 7 weeks [57] and 5 weeks [58]. A cut-off point of 14 days was chosen to define 'doctor delay' after taking into consideration a reasonable time period for sputum examination and chest x-ray before commencement of treatment. An acceptable period for both diagnostic and treatment time period is one week for each. One week is adequate to determine whether a patient has TB in a straight forward case. According to the national guidelines, at least 3 sputum samples are needed: spot, morning and spot specimens are collected over a period of 2 days. In the absence of chest x-ray, a patient with 2 positive smears can be started on treatment. Patients are started on treatment by medical officers almost immediately after diagnosis. Possible delay in starting treatment may occur if there is no medical officer in the health facility (often manned by medical assistants) which is common in Sabah. This 'delay' has been taken into account in the choosing the cut-off point of 14 days for doctor delay.

The median for doctor time period of 20 days (2.9 weeks) is much shorter than that found in the West Malaysian studies but comparable to the Nepal study (21 days)[75], Taiwan study (23 days)[76] and Hunan study, China (24

days)[83]. This value is probably in the middle range of doctor time period among studies which have used the same definition for doctor time period; from 6 days in Ethiopia[66], 11 days in Queensland[70], 5 weeks in Botswana[65] and 8 weeks in Ghana[72].

In Sabah, almost 43% of the respondents were put on treatment within 14 days of being seen by a medical doctor. In Ethiopia, the median time from first medical consultation to time of diagnosis was 6 days. About 53% were put on treatment within 6 days of being diagnosed and 90% within 15 days.[66] The short doctor time period of about 12 days on average was attributed to the high degree of alertness of the health staff on the possibility of TB as the prevalence of TB in Ethiopia is high and also the ease of making the diagnosis due to the advancement of the disease at consultation. For health centres where diagnosis was made late, it was due to shortage of laboratory technicians.[66]

The median period from consultation at a medical facility to commencement of treatment in Tanzania was 15 days with a large difference between urban and rural areas; 13.5 days versus 41.5 days attributable to the difference in accessibility of health services and also the educational level and knowledge of the patients.[73] This median of 15 days was also similar to that found in the New York study and also varied between those who were evaluated as out-patient and in-patients; 21 days versus 10 days.[64]

In contrast, in three quarters of the respondents in the Teheran study, diagnosis was made more than 1 month after medical consultation and which the authors implied lack of awareness and skills in making diagnosis of TB were to blame.[67] Even in a developed country such as UK, the median health service delay was 29.5 days with a shorter delay among those born in a high-prevalence country and those seen at the A&E (Accident and Emergency). This maybe due to the fact that those who came in through the A&E tend to be more ill and thus investigated more thoroughly.[60]

9.4.4 Explanatory factors associated with doctor delay

According to the authors of the two studies in West Malaysia, most of their respondents consulted private practitioners for their symptoms but most patients were diagnosed when they eventually sought treatment at government clinics. The authors suggested that due to the lack of awareness of TB among private practitioners, such long doctor time periods occurred. Similar reason for delay among private practitioners has been suggested in other studies such as in South Africa[63] and Philippines[84]. In South Africa study, patients who presented with TB symptoms were not diagnosed and referred to the hospital. Two thirds of them presented to hospitals after self-referral or at the insistence of family members, friends or employers. This reflected the quality of services provided by such groups which could have contributed to longer doctor delay.[84]

Doctor time period reflects both on the management of patients after consultation with a medical doctor and the behaviour of the patients in relations to the services provided. This thesis demonstrates that most patients in Sabah did not have problems complying with the requirements by the health providers such as sputum examinations and chest x-ray. In this study, more than 95% of respondents provided all 3 sputum specimens within 4 days of request and almost all respondents had their chest x-ray done within 2 days. Therefore, the doctor time period reflected more on how they were managed by the doctors in attendance.

Those who have never used government facilities mainly preferred private doctors as their first provider. It is possible that there exist certain 'profiling' on patients who sought treatment from private clinics. TB may not be suspected among patients of better socio-economic standings or in the absence of physical findings and with common symptoms such as cough and fever. In the South Africa study by Pronyk et al, the speed of diagnosis was higher among those who fitted the conventional risk profile of a TB suspect; those with history of migrant labour and alcohol consumption. In addition,

women tended to be diagnosed much later which the authors suggested maybe due to their (lower) socio-economic and cultural position in society.[63]

Other studies found that those who sought traditional healers were more likely to have 'doctor or diagnostic or health service' delay [26, 33, 65, 73, 83] most probably because these healers were not trained to diagnose diseases such as TB. In other studies, those who presented to the general practitioners were more likely to have 'doctor or diagnostic or health service' delay [26, 60, 71, 75] presumably due to a lower index of suspicion among general practitioners of the possibility of TB.

In the multivariate analysis, those who had never used government facility, had chest pain and loss of weight were twice more likely to be associated with doctor delay. A repeat visit to the first provider resulted in approximately 4 times doctor delay than those who did not (AOR: 3.88, CI: 1.79 - 8.39).

Those who had chest pain were almost thrice more likely while those with loss of weight were twice more likely to have doctor delay. This may be due to them being suspected of having other diseases; chest pain can often be suspected as related to a heart condition and loss of weight when not profound could often be treated symptomatically. Loss of weight could be due to loss of appetite as a result of other illnesses. A repeat visit to the first provider will prolong the doctor time period and may result in doctor delay. Again the reason for repeat visits might be that the attending doctors could have diagnosed the patient as suffering from other diseases.

The explanatory factors for doctor delay of more than 60 days differ from those for doctor delay of 14 days except for repeat visit to first provider. Those with fever tend to have doctor delay of more than 60 days probably because it is a non specific symptom which may be construed as not a very serious symptom by the attending doctors.

The median time period for doctor delay in this Sabah study is surprisingly lower than measured in West Malaysia. The incidence of TB in Sabah is the highest in Malaysia and perhaps the level of awareness on TB among private practitioners is adequate but need to be heightened. Sputum or chest x-ray examinations are often not available in all private clinics which may be a reason why patients were often treated symptomatically. For example, when a patient sees a private practitioner, in the absence of laboratory facilities, there may be a tendency to treat the patient's symptoms rather than subject the patient to laboratory examination elsewhere.

For doctor delay of more than 14 days, the main risk factors were repeat visit to the first provider and chest pain. A patient who had to revisit his/her first provider is four times more likely to have doctor delay while those with chest pain would be twice more likely to have doctor delay. For doctor delay of more than 60 days, a repeat visit to the first health provider would also result in delay and so was having fever as a symptom. In this Sabah study, 24% (95% CI: 19 - 29.5) of respondents had doctor delay of more than 60 days. The figure was higher in Botswana where 41% of the patients were put on treatment more than 8 weeks after medical consultation.[65]

In the Lusaka study, repeat health encounters contributed to diagnostic delay. This is because in Lusaka, diagnosis and treatment are provided at a central Chest Clinic.[26] In the Ethiopian study, similar to the Sabah findings, socio-demographic variables were not associated with health service delay. However, those living more than 30 minutes walking distance were more likely to have health service delay of more than 15 days.[66]

In New York, the explanatory factors for health care system delay were absence of cough, being smear negative, had chest x-ray more than 1 day after presentation to a medical provider and being homeless which seemed reasonable to cause delay.[64]

9.5 Contribution to current body of knowledge

It is also encouraging to know from the study that almost 90% of the respondents sought medical doctors in both government (~73%) and private sectors. This could allow for greater focus on these groups of professionals who can be monitored by the Ministry of Health especially in terms of standards of practice. Few patients (4%) self-medicate or seek traditional medicine. This is in contrast to 14% in the Lagos study[68] and Malawi[129] and 15.4% in South Africa[63] and 16% in Zambia[26] who sought non modern medicine such as traditional healers and prayer houses. In Tanzania, almost 39% of the patients first visited a traditional healer.[73]

In addition, the study also revealed the availability and accessibility of health services in Sabah. Slightly more than half of the respondents lived within 15 minutes of travelling time to the nearest health facility and almost 86% within 30 minutes of travelling time.

9.6 Improvement for future studies

Minimising recall bias would improve the internal validity and credibility of future studies in the same area. Although recall of events is affected by the personal characteristics, perhaps some methodological approaches can be modified towards minimising recall bias. Often interviewers do not explain in great detail the objectives of the study for various reasons. However, in studies such as this, active participation of the respondents is crucial. Patients are sometimes presented with 'prompts' to facilitate recall but it might be that patients need a different way of recalling events. These 'prompts' could be identified by doing a focus group discussion among TB patients and allowing time and efforts by the patients to recall events.

In addition to the above, other proxy sources such as clinical records should be used. Again, it may be beneficial to discuss the record with the patients to get as accurate data as possible. In this way, patients can used these clinical records as health diaries to improve recall. However, this involves a conscious

effort on the part of health staff to document systematically the onset of symptoms.

A further refinement of this type of study is to follow up a sample of patients who first presented with cough and those who eventually developed TB. One is then able to assess the time period between onset of symptoms and the other 'milestones' such as diagnosis and treatment. Needless to mention, this involves a lot more resources.

10 CHAPTER 10: Recommendations and conclusion

This chapter describes the potential implications of the study findings on current practice and future initiatives.

10.1 Implication towards current practice

This study has demonstrated that socio-demographic characteristics of the patients were not important explanations for delay in presenting with TB in Sabah, Malaysia. However, it highlighted the need to look beyond these characteristics and address some of the issues pertaining to health services discussed further here.

a. Greater awareness and adherence to existing guidelines

Almost 90% of the patients in this study sought either government or private doctors for cure. This health care utilisation pattern allow for concentration of efforts towards 2 main groups; the government clinics and private practitioners. Intensification of efforts towards raising awareness and index of suspicions for patients with cough is possible with these two groups. This will ensure that in addition to performing sputum examinations among patients with cough of more than 2 weeks, patients will not be subjected to repeated visits. This can be done by ensuring the use of the Practice Guidelines for the Control and Management of Tuberculosis issued by the MOH Malaysia by all practising doctors both in the government and private sectors.

b. Health education messages

The findings of this study could also support the incorporation of new messages in the health education materials especially at correcting misconceptions regarding cause, transmission and infectivity. Infectivity of TB could be explained in greater detail to lessen stigma towards TB patients. For example, it would help if people knew that TB could not be transmitted through sharing of utensils and is easily treated and became non infectious after a few days of treatment. From this study, it is quite clear that patients and the community knew where to get treatment and are able to request for sputum examination. These practices should be further encouraged. In addition, it is imperative that the public are able to recognise the

symptoms of TB and also appreciate the grave consequences of TB, not only to its patients, but also to the community at large.

The appropriate channel for health education messages also need to be identified. In a study done in North and Middle Vietnam, the knowledge of TB patients was high in terms of causes, infectivity and treatment (average score out of 10; 7.07 ± 2.02). There was significant difference between those who were given the health education in a face-to-face approach compared to other approach such as the distribution of leaflets (p-value <0.001).[13] In the West Malaysia study, the mean score for knowledge on TB was much higher among the patients who were given health education by their attending doctors compared to those who received them from other sources such as friends and media.[94] Currently, there is little evidence to suggest that knowledge on TB affects health seeking behaviour and time period significantly though this may be difficult to assess. It is perhaps more appropriate to conduct such research in the community rather than among TB patients who have already sought treatment.

c. Counselling for TB patients

The effects of TB on its sufferers were documented in this study. Efforts towards providing counselling for TB patients should be intensified. The current good relationship between the patient and health care provider could facilitate this process. Counselling should also be available after the completion of treatment because of the residual 'ill-health' felt even after cure as shown by Chamla among Chinese patients [98] and among Indian patients by Rajeswari[120].

d. Dissemination of research findings

The findings from the qualitative study have been disseminated to senior health staff and those involved in the TB Control Programme in Sabah. These findings and those from the quantitative study should be disseminated to a wider audience which should include the patients, community and other health staff. This could be done by publishing the results and also incorporating the relevant findings in health education materials.

Research findings may not always change policy but with the dissemination of research findings, through new understanding, greater awareness and insight on certain issues may result in attitudinal change among health staff to support improvement in service delivery.

10.2 Future initiatives

10.2.1 Delay and transmission

The longer a smear positive PTB patient delay seeking treatment, the higher the risk of transmission to close contacts. Earlier works by Riley have shown that delay of more than 2 months after onset of symptoms has been shown to spread TB to domestic contacts.[30] The median patient time period in this study is 60 days. This mean than half of the 272 respondents had potentially spread the disease to domestic and work contacts. The numbers of domestic contacts are substantial as some household have as many as 21 occupants with an average 6 people per household. In addition, for 75% of the respondents, the ratio of occupants to rooms in their household was two or more. Although the assessment of transmission within domestic contacts using these data is inaccurate, it does present a worrying picture and strengthens the need for symptomatic patients to seek treatment early and be put on treatment urgently. Contact tracing in Sabah has often been difficult to accomplish to a satisfactory level in terms of completeness and yield. In areas where resource such as manpower is limited, it may be worthwhile concentrating contact tracing effort to those patients with patient delay of more than 60 days.

10.2.2 Delay and Quality Assurance Programme

Reducing doctor delay can be used as an indicator for a Quality Assurance Programmes (QAP) for TB Control Programme. From this study, only 42.7% of the respondents have no doctor delay of 14 days. To increase the number of patients with no doctor delay would limit the period of infectiousness of the patient and thus the transmission to contacts. For example, the target could be set at a higher level of 90% and failure to achieve this would result in investigation as to why the patient failed to be put on treatment within 14 days of consulting a doctor. Based on the national guideline, a model of good care as required for a QAP can be

constructed. One of the reasons for doctor delay may well be the failure to subject the patients to sputum examination at the first consultation even when patients presented with cough of more than 14 days. Such finding and the rigor of investigation may contribute to raised awareness and change in attitude and practice. More thoughts should go into this idea and when constructed properly may not be difficult to implement as the concept of QAP is not new in Malaysia. The positive aspects of QAP in other programmes such as raised awareness on detrimental practices and identification of shortfall in quality when applied to TB control programme can only be beneficial.

10.3 Future research

This study has exposed information about health and health care seeking behaviours among certain ethnic groups. This needs to be extended to other ethnic groups and also among immigrant populations. Notification rates among immigrant population is also high; ranges from 100 to 150 cases per 100 000 populations.[5] Studies among immigrants and refugees revealed that politico-economic and social factors such as fear of immigration authorities[30], poverty and poorly ventilated holding places and subsequent living environment among Chinese immigrant in New York[130] resulted in patient delay. Similar social problems such as fear of immigration authorities are faced among illegal immigrants in Sabah which would affect their health care seeking behaviour.

This study has uncovered risk factors for patient and doctor delay which were not realised before. Future research can be replicated with better control for the limitations already mentioned in 9.3 above. In addition, the research could also assess the effects of delay among patients and their families and the consequence of delay in relation to prolong transmission in the community.

Research can also be build based on the current findings such as exploring the reasons for patient and doctor delay such as why delay occurs when patients chose private practitioners as their first choice for treatment and best done using qualitative methods.

10.4 Conclusion

This study which utilised both qualitative and quantitative approaches provided a comprehensive picture of health and health care seeking behaviour among certain population in Sabah and how these factors affected the various time periods in the management of TB patients.

The findings from both studies can be used to improve current practices such as the adherence to national guideline on the management of TB, provision of appropriate health messages, counselling for TB and creating greater awareness among health professionals on the patients and community perspectives of TB. New initiatives could also be drawn based on the findings of the study in terms of concentration of limited resource in areas where it will produce better results for the TB control programme such as in contact tracing and the development of a QAP programme. This study also opens up new areas for future research such as reasons for delay when consulting private doctors.

Appendix 1: TABLE ON STUDIES ON DELAY

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
STUDIES REPORTING DELAY USING MEDIAN							
1	Aoki M., Japan, 1985[74] Studies on factors influencing patient's, doctor's and total delay of TB case detection in Japan.	Survey	**Median patient's delay:** 17 D **Median doctor's delay:** 31 D **Median total delay:** 54 D	**Patient's delay:** from onset of symptoms to first visit to a doctor **Doctor's delay:** From first visit to a doctor to diagnosis **Total delay:** From onset of symptoms to diagnosis (desirable period=2 months)		Median doctor delay shorter if x-ray was done at the first medical institution.	
2	Auer C, Philippines2000[84] Health seeking and perceived causes of TB among patients in Manila, Philippines.	Cross sectional, 302 smear positive patients Instrument: Semi-structured interview	**Median lag time:** 1 month.	The use of lag time to denote health seeking delay.	Lag time was longer than 4 weeks among those who felt ostracised because of their illness (X^2=3.9, p=0.05)		
3	Bai LQ, 2004 [83] Factors associated with diagnostic delay	Cross sectional, 318 smear positive PTB. Instrument:	**Median patient delay:** 30 D **Median health system delay:** 24D	Article in Chinese (Abstract: English)	Longer delay if ▪ hemoptysis ▪ far distance from health institute	Longer delay if ▪ female ▪ low level of education	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	for patients with smear-positive pulmonary TB in rural Hunan, China.	Questionnaire	**Median total delay:** 65 D		▪ seek folk therapy ▪ low income	▪ prior health education on TB ▪seek folk therapy ▪ stigma associated with TB	
4	Barker R.D., South Africa, 2006[131] Traditional healers, treatment delay, performance status and death from TB in rural South Africa	Cross sectional, 133 smear positive PTB patients. Instruments: Data abstraction from National TB Register and 3 specific questions	**Median Treatment delay:** 60D (range: 0 – 210D)	**Treatment delay:** From first seeking treatment to starting treatment		Median time longer for those who consulted traditional healers (TH) compare to GP or hospital (GHS). Median (TH): 90D (range: 0-210D) Median (GHS): 21D (range: 0-120D)	
5	Chiang C-Y, Southern Taiwan, 2005[76] Patient and health system delays in the diagnosis and treatment of tuberculosis in Southern Taiwan.	Cross sectional, 206 new smear positive TB patients. Instrument: Questionnaire Analysis: Cox proportional hazard model	**Median patient delay:** 7D, IQR: 1 – 28D, range: 0 – 730D **Median health system delay:** 23D, IQR: 5 – 51D, range: 0 – 489D **Median total delay:** 44D, IQR: 19 – 82D, range: 0 – 730D	**Patient delay:** the interval from the onset of any symptom to the first medical consultation with a qualified doctor. Cut-off point: 30D **Health system delay:** the interval from the first medical	<u>Univariate analysis:</u> Shorter delay with ▪ age ≥ 65 years old <u>Multivariate analysis:</u> None	<u>Univariate analysis:</u> Shorter delay with ▪ male ▪ smear positive ▪ hemoptysis ▪ CXR at first consultation ▪ hospital as entry point Longer delay if patient has cough	<u>Univariate analysis:</u> Shorter delay with ▪ age ≥ 65 years ▪ smear positive Shorter delay if patient has cough only. <u>Multivariate analysis:</u>

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
				consultation to the initiation of anti-TB treatment. Cut-off point: median **Total delay:** the interval from the onset of any symptoms to the initiation of treatment.		only <u>Multivariate analysis:</u> Shorter delay if ▪ smear positive (AOR: 1.76, CI: 1.30 – 2.38) ▪ hemoptysis (AOR: 1.68, CI: 1.14 – 2.48) ▪ CXR at first consultation (AOR: 1.90, CI: 1.43 – 2.54)	Shorter delay if ▪ age ≥ 65 years (AOR: 1.39, CI: 1.05 – 1.85) ▪ smear positive (AOR: 1.66, CI: 1.23 – 2.25) Longer delay if has cough only (AOR: 0.73, CI: 0.53 – 0.99)
6	Date J, Yemen, 2005[80] Gender and literacy: factors related to diagnostic delay and unsuccessful treatment of tuberculosis in the mountainous area of Yemen.	Cross sectional, 74 new smear positive patients. Instrument: Questionnaire	**Median diagnostic delay:** 8 weeks	**Diagnostic delay:** Interval between the onset of signs and symptoms and the diagnosis of TB.		<u>Univariate analysis:</u> Literacy and patient recognition of TB were associated with delay (p=0.006 & p=0.011). <u>Multivariate analysis:</u> Illiterate patients delay longer (AOR: 2.9, CI: 1.0-7.9, p=0.04)	
7	Dembele S.M.,	Retrospective	**Median Time to**	**Time to arrival at**		Median time to arrival	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	Burkina Faso, 2006[132] Are patients who present spontaneously with PTB symptoms to the health services in Burkina Faso well managed?	survey, 6 health districts, 248 730 smear positive TB patients, Instrument: Registry and medical records	**arrival at the CDT (Centre for Diagnosis & Treatment):** 1D (range: 0 - 79D) **Median time to start of treatment:** 1D (range: 0 – 6D)	**the CDT:** the time between the first consultation and the first smear examination at the CDT **Time to treatment:** time between the first smear examination and the start of treatment at the CDT		and time to start of treatment differ between health districts and related to efficiency of the system and competency and motivation of health staff.	
8	Demissie M, Ethiopia, 2002[66] Patient and health service delay in the diagnosis of pulmonary TB in Ethiopia.	Cross sectional, 700 PTB patients (320 smear positive and 380 smear negative) Instrument: Questionnaire & patient's record	**Median patient delay**: 60 D **Median health service delay**: 6 D **Median total delay**: 64 D	**Patient delay**: time interval from appearance of major pulmonary symptom to first visit. (use 1 month to dichotomise patient delay) **Health service delay**: first consultation to diagnosis. **Total delay**: The sum of patient delay and health service delay	Longer delay if ▪ Distance from home to health institution (>1 hour walking distance): OR: 2.56 (CI: 1.1.2-6.03) (smear negative) ▪hemoptysis in both smear positive (OR:1.90, CI:1.16-3.12) and smear negative (OR:1.91, CI:1.23-2.95) Less likely to delay if ▪ those who know	Smear positive are less likely to be undiagnosed for >15 days. Those who lived >30 min walking distance are > likely to delay >15 days. Walking distance: ▪ 30–60 min: OR:1.68, CI:1.06-2.66 ▪ 60-120 min:	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
					modern medicine are less likely to delay (OR:2.93, CI:1.00-9.18)(smear negative)	OR:2.97, CI:1.30-6.88 ▪ >120 min: OR:3.38, CI:1.33- 8.83	
9	Diez M, 2004 [62] Determinants of patient delay among TB cases in Spain.	Cross sectional, 7037 patients in 13 autonomous regions. Instrument: Clinical records Analysis: Logistic regression	**Median patient delay**: 22 D 2 cut-off points: median and 75th percentile	Definition: Same as above.	Longer median if: ▪ age > 14 years (all OR >3.0) ▪ has non respiratory symptoms (OR:1.47, CI: 1.32-1.63) Longer delay (75th percentile) ▪ same as above ▪ alcoholism (OR:1.19, CI: 1.01-1.42) ▪ female (OR:1.15, CI: 1.01-1.30) <u>Multivariate analysis:</u> ▪ history of recurrence (AOR: 0.82, CI: 0.69-0.97) ▪ presence of respiratory symptoms (AOR: 0.83, CI: 0.72 –		

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
					0.95) ▪ presence of pulmonary & extra-pulmonary disease. (AOR: 0.80, CI: 0.68-0.93)		
10	Gagliotti C, Italy, 2006[77] Delay in the treatment of pulmonary TB in a changing demographic scenario	Cross sectional, 271 PTB patients Instrument: Routine data, Interviews and medical records	**Median patient delay:** 7D **Median health care delay:** 36D **Median total delay:** 65D	**Patient delay:** from onset of TB symptoms to first consultation with a health provider **Health care delay:** from first consultation with a health provider to initiation of treatment **Total delay:** from onset of TB symptoms to initiation of treatment	<u>Multivariate analysis:</u> Those who stayed in Italy ≤ 3 years had long patient delay (AOR: 2.13, CI: 1.18 – 3.87)	<u>Multivariate analysis:</u> Long delay if ▪ migrant (AOR: 2.26, CI: 1.16 – 4.38) ▪ Consult other than chest physicians (AOR: 2..66, CI: 1.33 – 5.34) ▪ cough < 1 month (AOR: 2.2, CI: 1.08 – 4.51)	
11	Golub J E, Maryland, USA, 2005[59] Patient and health care system delays in pulmonary	Prospective cohort, 158 patients	**Median patient delay:** 32 D (range 0-539D) **Median health care delay:** 26 D (range 0-519D)	**Patient delay:** from first TB symptoms to first health care visit **Health care delay:** from first consultation with a medical	<u>Longer delay</u> if ▪ Non-white patients (RH 0.62; CI 0.39-0.98) ▪ less than 12 years of education (RH 0.43; CI	<u>Longer delay</u> ▪ age > 50 years (RH 0.67; CI 0.44-1.03) ▪ speak English (RH 0.40; CI 0.24-0.68) ▪ history of asthma	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	tuberculosis diagnosis in a low-incidence state[59]			provider to initiation of treatment **Total delay:** from first onset of symptoms to initiation of treatment	0.26-0.72) ▪ no respiratory symptoms (RH 0.29; CI 0.11-0.71) ▪ patients with no asthma (RH 0.51; CI 0.30-0.89)	(RH 0.51; CI 0.27-0.97) ▪Antibiotic for initial diagnosis (RH 0.69, CI 0.49-o.96) ▪Has insurance (RH 0.7, CI 0.48-1.03) <u>Shorter delay</u> ▪ presenting with cough (RH 2.05; CI 1.20-2.50) ▪ those with increasing patient delay (RH 1.28; CI 1.09-1.49) ▪ attend hospital emergency (RH 1.87; CI 1.05-3.33) ▪ public health clinic (RH 1.79; CI 1.21-2.63) ▪ positive smear (RH 1.69, CI 1.15-2.48) ▪Skin test done (RH 1.62, CI 1.16 – 2.24)	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
						•Had sputum specimen (RH 5.42, CI 3.37-8.71) •CXR done (RH 2.13, CI 1.36-3.34) •Suspect TB by CXR (RH 1.6, CI 1.07-2.39)	
12	Guneylioglu D., Turkey, 2004 [78] Factors affecting delays in diagnosis and treatment of pulmonary TB in a tertiary care hospital in Istanbul, Turkey.	Cross sectional (tertiary hospital), 204 smear positive TB patients Instruments: •Clinical files •Questionnaire	**Median application interval:**17.5 D (95% CI : 26.1 – 36.7) **Median referral interval:**11.0 D (95% CI : 18.1 – 26.2) **Median diagnosis interval:**1.5 D (95% CI : 2.5 – 4.0) **Median treatment interval:**1.0 D (95% CI : 1.2 – 1.7) **Median doctor delay** (referral interval + diagnosis	**Patients' application interval:** time interval between onset of symptoms and first doctor's visit. [Patient delay: Interval> 30 days] **Referral interval:** time from first doctor visit to admission. [Institutional delay: Interval of > 2 days] **Diagnosis interval:** time from admission to a positive acid-fast smear. [Delayed diagnosis: Interval > 1 day]	Longer if ▪ no index cases (p=0.04) ▪ poor economic status (p=0.03) Less likely to have patient delay if ▪ has hemoptysis (p=0.04)	**Shorter referral interval if:** ▪ male (p=0.015) ▪ referred by chest physician (p-value=0.043)	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
			interval + treatment interval): 15 D	**Treatment interval:** time from diagnosis to initiation of treatment. [Delayed treatment: Interval > 1 day] **Clinic delay:** time from admission to initiation of treatment. [Delay: Interval > 2 days] **Doctor delay:** time from first doctor visit to initiation of treatment. [Delay: Interval > 4 days]			
13	Hooi LN, Malaysia, 1994 [58] Case-finding for pulmonary TB in Penang. Malaysia,	Cross sectional, 100 PTB patients Instrument: Medical records and interview	**Median total delay:** 3 mths **Median patient delay:** 2 wks **Median doctor delay:** 5 wks	**Patient delay:** from the onset of illness until initial medical consultation. **Doctor delay:** from consultation to commencement of treatment.	Longer in ▪ males ▪ those with lower than secondary education ▪ drug abusers (all with p<0.01).	Shorter **doctor delay:** ▪ those who first consulted government medical facilities than those seeking treatment from private practitioners.	
14	Lawn SD, Ghana,	Cross sectional,	**Median total delay**	**Total delay:** from		**Increased doctor**	**Total delay in**

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	1998[72] Pulmonary TB: diagnostic delay in Ghanaian adults.	100 newly diagnosed smear positive patients Instrument: Questionnaire	**in diagnosis:** 4 mths **Median patient delay:** 4 wks **Median doctor delay:** 8 wks	onset of symptoms to diagnosis. **Patient delay:** from onset of symptoms to first consultation. **Doctor delay:** from first consultation until diagnosis.		**delay:** ▪ females ▪ rural patients ▪ those needing hospitalisation. Strongly correlated to rate of failure to perform sputum microscopy particularly among private practitioners and rural government facilities.	**diagnosis:** Strongly associated with rural residence (p=0.001).
15	Liam CK, Malaysia, 1997[57] Delay in the diagnosis and treatment of pulmonary TB in patients attending a university teaching hospital. Kuala Lumpur, Malaysia,	Cross sectional, 97 newly diagnosed PTB (36 smear positive, 61 smear negative) Instrument: Questionnaire	**Median total delay:** 12.5 wks **Median patient delay:** 2 wks **Median doctor delay:** 7 wks				
16	Lienhardt C, The Gambia, 2001[69]	Cross sectional, 152 patients; 110	**Median total delay** : 8.6 wks	**Patient delay:** from onset of symptoms to			Longer delay ▪25-34 years old

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	Factors affecting time delay to treatment in a TB control programme in a sub-Saharan African country: the experience of The Gambia.	males and 42 females. Instrument: Questionnaire, Focus group discussion Analysis: Kaplan-Meier survival analysis and Cox proportional analysis model	(IQR: 5 -17), **Median total delay:** 8 wks (IQR: 4-12) (urban), 12 wks (IQR: 8.5-17) (rural) and 13.5 wks (IQR: 4-17) (foreigners).	1st visit to health care provider. **Health provider delay:** from 1st visit to health care provider to 1st visit to LTI (Leprosy/TB Inspectors). **Diagnosing facility delay:** from 1st visit to LTI to start of treatment. **Total delay:** from onset of symptoms to start of treatment.			(Adjusted hazard ratio: 0.54, CI: 0.32-0.91, p-value=0.02) Shorter delay ▪Urban are (Adjusted hazard ratio: 1.85, CI: 1.15-2.98, p-value=0.01) Shorter median delay if: ▪hemoptysis at onset vs those without (3 wks, IQR: 1.5-6 vs 8 wks, IQR: 4-13) ▪seen by hospital or private doctor.
17	Moro ML, Italy, 2003[85] Diagnostic delay in patients with pulmonary TB.		**Median delay from onset to diagnosis:** 55 D	Article in Italian.			Longer delay when; ▪ GP as the first provider ▪ clinical picture has not manifested fully.
18	Needham DM,	Cross sectional,	**Median diagnostic**	**Diagnostic delay:**		**Diagnostic delay**	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	Zambia, 2001[26] Socio-economic, gender and health services factors affecting diagnostic delay for TB patients in urban Zambia.	225 smear positive and negative patients (202 completed interviews) Instrument: In-depth interview	**delay :** 8.6 wks	time from symptom onset to initiation of therapy.		**associated with:** ▪ female (p-value=0.02) ▪ lower education (p-value=0.04) ▪ > 6 instances of health-seeking encounter(p-value<0.001) ▪ OPD diagnosis of TB (p-value=0.03) ▪ Visit private doctor (p-value=0.05) or traditional healer (p-value<0.001)	
19	Odusanya O. 2004 [68] Patterns of delay amongst pulmonary TB in Lagos, Nigeria.	Cross sectional, 141 patients: 89 males and 52 females. 116 positive smears Instrument: Questionnaire	**Median patient delay:** 8 wks **Median doctor delay:** 1 wk **Median treatment delay:** 1 wk **Median total delay:** 10 wks	**Patient delay:** Interval between onset of symptoms and first contact with a health facility (cut-off: 30 days) **Doctor delay:** time between visit to first facility and the chest clinic (cut-off: 15 days)	Not associated with socio-demographic factors.		

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
20	Paynter S., London, UK, 2004[60] Patient and health service delays in initiating treatment for patients with pulmonary TB: retrospective cohort study.	Retrospective cohort, 71 patients Instrument: Hospital data, notification form, GP data Method of diagnosis: Chest X-ray	**Median case finding delay:** 78D (IQR: 39-159D) **Median patient delay:** 34.5D (IQR: 14-62D) **Median health service delay:** 29.5D (IQR: 8-80D) **Median delay between GP referral to chest clinic and attendance:** 14D **Median delay between GP request for CXR and referral to chest clinic:** 9D	**Total case finding delay:** from onset of symptoms to initiation of treatment **Patient delay:** onset of symptoms to first contact with health services **Health service delay:** first contact with health services to initiation of treatment	Longer in: ▪ age >33 years ▪ born in a low prevalence country	Longer in: ▪ those who present to GP ▪ born in a low prevalence country Less delay in: ▪ sputum smear positive ▪ younger patients	▪ age >33 years ▪ born in a low prevalence country Less delay in: ▪ sputum smear positive ▪ those who presented first to A&E
21	Pronyk RM, South Africa, 2001[63] Assessing health seeking behaviour among TB patients in rural South Africa.	Cross sectional, 298 patients: > 10 yrs old, new and re-treatment, include sputum negative patients Instrument:	**Median total time to hospital:** 10 wks (range 0-550 wks). Rate of hospitalisation/100 person-wks coughing in the	Delay data presented in median and incidence rate. (Rate=d/W, d=no. of events, W=total number of person-weeks).	Lower among ▪those who present to hospital than those to clinic or GP (RR=1.49, CI; 1.16-1.89). Used of hazard ratio.	**Greater delay to hospitalisation** ▪those who present to hospital than to clinic or GP (RR=1.33, CI: 1.13-1.85).	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
		questionnaire	community = 4.6. **Median patient delay:** 4 wks (range 0-466 wks). Rate of presentations to health providers/100 person-wks coughing in the community=7.2. **Median service provider delay:** 1 wk (Range 0-208 wks). Rate of hospitalisation/100 person-wks actively seeking a diagnosis=15.6. **Median service provider delay** for those who initially presented to health provider: 2 wks.	Patient delay is divided into patient and traditional healer delay.	Statistically significant for **patient delay:** ▪ number of persons in household (>4).	Used of hazard ratio. For **service provider delay**, statistically significant if: ▪ female ▪ ever drank alcohol ▪ had been a migrant worker ▪ distance from clinic (>5 km) ▪ believed TB to be caused by bewitchment	
22	Rajeswari R, India, 2002[71] Factors associated	Cross sectional, 531 smear positive patients. Instrument:	**Median patient delay:** 20 D **Median health service delay:** 23D	The same as above. Patient delay was *dichotomised using a* cut-off value of 30	Statistically significant ▪ Age <45 years old ▪ illiteracy ▪ family income	▪ Distance ≤ 2 km ▪ government as first provider ▪ cough duration ≤ 1	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	with patient and health system delays in the diagnosis of TB in South India.	Questionnaire		days while for health system delay, dichotomised using a cut-off value of 7 days.	▪ distance <2km ▪ alcoholism ▪ government facility as the first provider. Multivariate analysis: longer patient delay: ▪ initial consultation with government provider: (Adjusted OR (AOR): 2.2, CI: 1.5-3.4, p≤0.001) ▪ residing > 2km from health facility (AOR: 1.6, CI: 1.0-2.4, p=0.04) ▪ self-reported alcohol use (AOR=1.6, CI: 1.0-2.4, p=0.04)	month. Multivariate analysis: ▪ first consultation with private (AOR-4.0, CI: 2.6-6.4, p<0.001) ▪ shorter duration of cough (AOR 1.8, CI: 1.1-2.8, p=0.02) ▪ distance > 2km (AOR-1.8, CI: 1.1-2.8, p=0.02) ▪ alcoholism(AOR 1.6, CI: 1.0-2.6, p=0.04)	
23	Salaniponi FM, Malawi, 2000[129] Care seeking behaviour and diagnostic processes in patients with smear-	Cross sectional, 1099 new smear positive PTB patients. Instrument: Questionnaire	**Median time between onset of cough and diagnosis: 8 weeks**				

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	positive pulmonary TB in Malawi.						
24	Sherman LF, New York, 1999[64] Patient and health care system delays in the diagnosis and treatment of TB.	Cross sectional, 184 culture positive TB patients Instrument: Medical record and interview	**Median total delay:** 57 D (4-764D), 35 D (smear positive) and 79 D (smear negative) ($p<0.001$). **Median patient delay:** 25 D (0-731D). **Median health care system delay:** 15 D, 6 D (smear positive) and 31 D (smear negative) ($p<0.001$).		Longer **patient delay:** ▪ age 55-64years old (AOR: 10.6, CI: 1.3 – 86.9) ▪ primary language other than English (AOR: 2.5, CI: 1.0 – 5.8).	Longer **health care system delay:** ▪ homelessness (AOR:7.1, CI: 1.05 – 33.5) ▪ no chest X-ray done at first visit (AOR: 2.4, CI: 1.0 – 5.4) ▪ negative smear (AOR: 10.2, CI: 4.4 – 23.3) ▪ absence of cough (AOR: 2.9, CI: 1.2 – 6.8)	
25	Steen TW, Botswana, 1998[65] Pulmonary TB in Kweneng District, Botswana: delays in diagnosis in 212 smear-positive patients.	Cross sectional, 212 smear positive TB patients Instrument: Questionnaire	**Median total delay:** 12 wks, **Median patient delay:** 3 wks, **Median health service delay:** 5 wks 54% seek treatment less than 4 weeks.	**Patient's delay:** number of weeks from the time of the first symptoms to the first consultation. **Health services' delay:** Number of weeks from the first consultation until the	▪ self-rated health: fair or good	Longer delay: ▪ first visit to a health post ▪ visit a traditional or faith healer ▪ stay in village without hospital ▪ self-rated health: poor or very poor ▪ being married	Longer delay: ▪ first visit to health post ▪ STD treatment during last 3 years ▪ registered on out-patient card ▪ visit to traditional healer prior to treatment

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
				start of treatment. **Total delay:** number of weeks from the first symptoms until start of treatment.			
26	Van der Werf M.J., Ukraine, 2006[82] Health care seeking behaviour for tuberculosis symptoms in Kiev City, Ukraine	Cross sectional, 190 newly diagnosed PTB. Structured questionnaire and medical records	**Median patient delay:** 30D, IQR 7 - 75D, range: 0 – 365D	**Patient delay:** Start of symptoms and first visit to a health care provider.	Univariate analysis: Longer if • jobless (p=0.003) • alcohol abuse (p=0.07) • smear positive PTB (p<0.001) Multivariate analysis: • unemployed (AOR:6.03, CI: 2.23-16.33) • employed in private sector (AOR: 3.27, CI: 1.03-10.35) • cough (AOR: 2.37, CI: 1.08-5.19) • weight loss (AOR: 2.37, CI: 1.08-5.19)		
27	Wandwalo ER, Tanzania, 2000[73]	Cross sectional, 296 new smear	**Median patient delay:** 120D	**Patient delay:** from onset of symptoms to	Longer mean: ▪ >45 years	Longer mean: ▪rural facilities	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	Delay in TB case-finding and treatment in Mwanza, Tanzania.	positive patients, ≥15 years old Instrument: Structured questionnaire, patient's record	**Median health system delay**: 15D **Median diagnosis delay**: 14D	being seen at a health facility (Maximum 'acceptable' delay: 30 D) **Health system delay:** from reporting to a health facility through diagnosis to commencement of treatment (Maximum 'acceptable' delay: 10 D)	▪ in rural settings ▪ >10 km from health facility ▪no information on TB prior to diagnosis ▪below primary school education ▪visit to traditional healer		
28	Ward J, Australia, 2001[70] Patient and health care system delays in Queensland TB patients, 1985-1998.	Analysis of TB Database 782 symptomatic confirmed cases either by bacteriologic or histological	**Median patient delay:** Total group- 29D Smear positive: 30D **Health care system delay:** Total group-22D Smear positive: 11D **Median treatment delay**: Both groups: 1D **Total delay:**	**Patient delay**: the difference between the date symptoms first noted by the patient and the date of first relevant presentation to a medical practitioner. **Health care system delay**: difference in days from the date of first relevant	Univariate analysis Shorter delay: ▪ migrant status Multivariate analysis Shorter delay: ▪ high risk migrant ▪ indigenous Australians	Longer health care system delay: ▪ increasing age ▪ increased length of stay in Australia (total group) ▪ non-migrant Multivariate analysis Shorter delay: ▪ male ▪ ≥ 45 years old	Shorter delay: ▪ indigenous Australians ▪ migrants

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
			Smear positive: 66D	presentation to a medical practitioner and the date of starting treatment (or diagnosis if no treatment was given) **Diagnostic delay:** difference between the date of first consultation and date of diagnosis. **Treatment delay:** difference between the date of diagnosis and the initial treatment date. **Total delay:** difference between date of onset of symptoms and treatment date.		(Total group) ▪ indigenous Australians (Total group) ▪ high risk migrants (smear positive)	
29	Wares DF, 1999 [133] Delay in diagnosis of TB: of remaining concern in England	Review of cases, 43 cases Instrument: Hospital data	**Overall median delay:** 7 wks.	Used "acceptable" period between onset to diagnosis as 30 days.	No difference between Whites and South Asians. Significant difference between median ages		

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	and Wales.				of both ethnic groups ($p<0.02$) and pre-existing medical risk factors (whites >South Asians)		
30	Yamasaki-Nakagawa M, Nepal, 2001[33] Gender difference in delays to diagnosis and health care seeking behaviour in a rural area of Nepal.	Cross sectional, 336 new cases of TB (all types) Instrument: Questionnaire Diagnostic method: sputum microscopy	**Median total delay:** 2.3 mths (men), 3.3 mths (women) **Median patient delay:** 0.8 mth (men), 0.6 mth (women) **Median health service delay:** 0.8 mth (men), 1.3 mths (women)	**Patient's delay:** from onset of symptoms to the first visit to a health care provider, including traditional healer **Health care provider's delay:** from first visit to diagnosis NB: defined as delay if > 1 month.	Shorter delay: ▪ if a health care provider exists within Village Development Committee	Among women, longer if: ▪ visited a traditional healer first	
31	Yimer S, Ethiopia, 2005[75] Diagnostic and treatment delay among pulmonary tuberculosis in Ethiopia: a cross sectional study	Cross sectional, 384 new smear positive cases ** 30D for pt delay which is also the median and 15D for health system	**Median Health providers' (HP) delay:** 61D (IQR 31-116D) **Median Patients' delay:** 30 D (IQR 15-90D) **Median Health Systems' delay:**	**Patient's delay:** from onset of symptoms to first visit to health provider **Health providers' delay:** from visit to health provider to start of treatment **Health systems'**	<u>Longer delay</u> in: ▪ lived beyond 10 km of a medical facility (OR=3.81, 95%CI, 2.21, 6.57) ▪ age > 45 years (OR=2.62, 95%CI, 1.13, 6.02) ▪ Self treatment	<u>Shorter HP</u> delay for: ▪ lived within 10 km of a medical facility (OR=0.42, 95%CI, 0.24, 0.72) ▪ went to school 1-8th grade (OR=0.56, 95%CI, 0.33, 0.97) ▪ 9th grade and above	

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
		delay after consultation	21D (IQR 7-60D) **Median Total delay:** 80D(IQR 44.2- 129.8D)	**(HS) delay:** from visit to medical provider to start of treatment **Total delay:** from onset to start of treatment	(OR=1.69, 95%CI, 1.04, 2.75)	(OR=0.40, 95%CI, 0.20, 0.81) ▪ those who attended formal health providers (OR=0.35, 95%CI, 0.20, 0.81) <u>Increased HS delay</u>: ▪ those who attended health post (OR=3.50, 95%CI, 1.86, 6.57) ▪ those who attended private medical providers (OR=2.10, 95%CI, 1.18, 3.71)	
STUDIES REPORTING DELAY USING MEAN							
1	Asch, S., California, USA, 1998 [30] Why do symptomatic patients delay obtaining care for TB?	248 symptomatic patients Instrument: Self reporting questions Analysis: Logistic regression	**Mean:** 74 days ± (SD:216 days)	Delay in seeking care of more than 60 days from onset of any symptoms.	<u>Multivariate analysis:</u> ▪ were unemployed (OR: 2.3, CI: 1.2-4.7) ▪ believed they could treat themselves (OR: 2.1, CI: 1.4-4.4) ▪ uncertain about where to get care (OR: 2.4, CI: 1.2-4.9)		

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
2	Chakraborty AK, India, 2001 [79] Missed opportunities for diagnosis of pulmonary TB: A study among rural patients seeking relief on their own under the TB Programme in India.	Cross sectional, 147 newly diagnosed smear positive TB patients in 2 areas (Area 1 and 2) Instrument: Questionnaire	**Total mean delay:** 10.7 mths (Area 1) and 9.6 mths (Area 2). **Mean patient delay:** 8.89 mths (Area 1) and 8.97 mths (Area 2). **Mean health system delay:** 1.81 mths (Area 1) and 0.67 mth (Area 2).	**Total mean delay:** interval between chest symptoms and final bacteriological diagnosis. **Patient delay:** interval between chest symptoms and action taken by patients for relief. **Health system delay:** interval action taken by patient and final diagnosis as TB.		Mean health system delay associated with gender, lower SE status and illiteracy.	
3	Masjedi MR, Teheran, Iran, 2002[67] Reasons for delay in the management of patients with pulmonary TB	Cross sectional, 30 males, 20 females. Instrument: Patient interview	**Mean patient delay:** 12.5± 7.5 D **Mean physician delay:** 93±80 D Mean delay for female (108 ± 93D) and male (70±60D) - significant statistically. **Mean treatment delay:** 4±4 D	**Patient delay:** time between onset to first medical consultation. **Physician delay:** time taken by physician to diagnose TB **Treatment delay:** time after diagnosis before treatment.	Male delay was significantly longer than female. Reasons for delay: ▪ under-estimation of symptoms (38%) ▪ too busy (6%) ▪ poor access (2%) ▪ no reason (14%) ▪ inability to get medical advice due to dependency on their		

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
					husbands (13% of females).		
STUDIES REPORTING DELAY USING OTHER CUT-OFF POINT							
1	Godfrey-Faussett, P. Zambia, 2002[18] Why do patients with a cough delay seeking care at Lusaka urban health centres? A health systems research approach.	Cross sectional, 427 patients with cough that has not been investigated before. Instrument: Questionnaire	35% (95% CI: 30.4-39.3) of patient delayed for more than 4 weeks.	Patient delay: Patient's recall of when symptoms of the current cough first started. Patient delay of more than 4 weeks as significant.	Associated with: ▪ age (p<0.001 for test for trend) ▪ increasing severity of illness p<0.001 for test for trend) ▪ poor perception of health service (lack of drug and previous experience) p=0.003 for test for trend) ▪ prior attendance to private clinic (p=0.04) ▪ distance from health centre (p=0.16)		
2	Habibullah S, Pakistan, 2004 [86] Diagnostic delay in TB and its consequences. Pakistan,	Cross sectional, 115 PTB patients Instrument: Hospital data?	Average time from onset to diagnosis and treatment: 120 days				▪ patients who consult private doctor (p=0.05) ▪ those with loss of weight and hemoptysis (p<0.05).
3	Okutan O. Turkey,	Cross sectional,	▪ Average time of				

No	Main author, country, year, Study title	Design, sample size, data collection method	Results	Definition & Interpretation	Factors associated with		
					Patient delay	Health provider delay	Total delay
	2001 [134] Time to beginning therapy and affecting factors among Turkish soldiers with pulmonary TB. An analysis of a Turkish Military Chest Diseases Hospital.	97 newly diagnosed patients with PTB Instrument: Questionnaire	admission to first primary doctor: 15.6 ± 13.7 ▪ From first visit to admission: 21.9 ± 19.4 ▪ From hospitalisation to start of treatment: 26.3 ± 18.4				
4	Tamhane A., India[61] Pulmonary TB in Mumbai, India: An evaluation of factors responsible for "delays" in seeking and initiating treatment.	Cross sectional, 75 men & 75 women smear positive Instrument: Medical records and interview	29% had patient delay, 81% had treatment delay.	**Patient delay**: seeking care after 20 days of onset. **Treatment delay**: treatment initiated after 14 days of first consultation.	Women were more likely to delay.	Those consulting non-allopathic provider were more likely to experience **treatment delay**. (OR: 14.3, CI: 1.9 – 110.6).	

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Appendix 2: Studies on the perception of TB

	Study, Author, Country	Ethnic group	Findings
1	TB beliefs among recent Vietnamese refugees in New York State. Carey JW, USA[87]	51 Vietnamese refugees (non TB participants)	▪ TB is an infectious lung disease Risk factor for TB: ▪ Hard manual labour, smoking, alcohol consumption and poor nutrition. ▪ Believed that asymptomatic latent infection is not possible and all infection inevitable leads to disease ▪ Anticipated that having TB would adversely impact their work, family, and community activities and relationships.
2	Different TB in men and women: beliefs from focus groups in Vietnam. Long NH.[88]	Vietnamese, 16 focus group discussions (FGD)(TB and non TB participants)	▪ Has good knowledge of TB as being a dangerous and contagious disease cause by germs. Prevailing traditional beliefs mainly among older people in the rural areas. Four main types of TB: (1)*'Lao truyen'* (hereditary TB), handed down from older generations through 'family blood', regardless of sex (2) *'Lao luc'* (physical TB), caused by hard work in which more men are affected (3) *'Lao tam'* (mental TB), caused by too much worrying and more women are affected (4) *'Lao phoi'* (lung TB), dangerous, caused by TB germs, transmitted through the respiratory system and more men are affected. These traditional beliefs may contribute to long delays and increased social stigma and isolation of TB patients and their families.
3	Sociocultural	217 Ethiopians	▪ Do not regard tubercle bacilli

	Study, Author, Country	Ethnic group	Findings
	aspects of TB control in Ethiopia. Vecchiato NL. [89]	(non TB participants)	to be the cause of TB. Prefer to seek ethno-botanical remedies.
4	Perceptions and practices related with TB and treatment compliance in Chiapas, Mexico. Alvarez-Gordillo GC.[90]	Mexicans, 11 group interviews with 67 TB patients	Perceived causes of TB: contagion via food utensils, excess work, malnutrition and cold as well as other causes unrelated to person-to-person contagion.
5	Patients' beliefs: do they affect TB control? A study in a rural district of South Africa. Edginton ME.[91]	Rural South Africans: Individual interviews with TB patients and FGD with patients and community.	Strong belief that TB is the result of breaking cultural rules such as not abstaining from sex after the death of a family member and after a spontaneous abortion. As such, the remedy can only be obtained from traditional healers.
6	Cultural meanings of TB in Aceh Province, Sumatra Caprara A., Indonesia[92]	Achehnese	TB is represented by a semantic network of illnesses, partly transmissible, partly related to specific phenomena affecting the individual, such as '*terbuk*' (poisoning) or '*trouk*' (fatigue produced by hard work) and are not considered contagious. The forms of transmission are interpreted mostly through empirical and analogical categories. TB is attributed to four different aspects: (a) biomedical such as germ theory; (b) socio-economic conditions; (c) transgression of social rules and (d) poisoning and the influences of supernatural powers. Health-seeking behaviour is related to the perceived causes of the disease, economic factors and the accessibility of health services.

	Study, Author, Country	Ethnic group	Findings
7	Health seeking and perceived causes of TB among patients in Manila, Philippines. Auer C.[84]	319 smear positive Filipinos.	Perceived causes of TB: ▪ Drying sweat on the back, smoking, microbe, drinking alcohol, dirty environment, sleeping on cold floor, fatigue, working too hard, frequent pneumonia, lack of food, poverty, to be near a TB case, inherited, many sex partners.
8	From their own perspective. A Kenyan community's perception of TB. Liefooghe R.,Kenya[93]	Kenyan tribes, 5 FGD (TB and non TB participants)	Perception of TB: Dangerous disease that is highly contagious and difficult to cure. A difficult disease that disrupts patients' social life leading to social isolation and stigmatization of the patients and their families.
9	Attitudes and knowledge of newly diagnosed TB patients regarding the disease, and factors affecting treatment compliance. Liam CK., Malaysia[94]	Malaysians (West Malaysia) (135 patients)	Attributed symptoms to: ▪ common cold (22%) ▪ 'weak' body (9.1%) ▪ overwork (6.8%) ▪ asthma(3.8%), lung cancer (3%), diabetes mellitus (2.3%), pneumonia (1.5%), TB (1.5%), dengue fever, heart failure ▪ cigarette smoking (3%) ▪ effect of an abortion ▪ a spell put on them by someone (1.5%)
10	Social and cultural factors in the successful control of TB. Rubel AJ [3]	Mexicans, Orange County, CA	Symtoms associated with ▪ benign conditions gripe (grippe) or bronquitis (bronchitis) ▪ a folk illness, susto ▪ fatigue and weight loss due to hard work and lack of sleep

Appendix 3: Topic guides for in-depth interview

PATIENT	
Recognition of symptoms	• How long have you been sick? • Do you remember the time when you first fell ill for this disease? • What makes you realise that you were not well? • What were the signs and symptoms at that time? • What did you think was the cause of your symptoms? • What disease did you think you have at that time?
Health seeking behaviour /pattern	• What did you do when you first realised that you were sick? • Who did you talk to about your concerns? • Did you follow the advice given? • What motivates you to seek such care? • What prevented you from seeking such care? (barriers) • Who decides what you should or should not do?
Perception of illness	• What did you think cause the illness? • What do you call this illness in your language? • What cause you to get this illness? • How does it affect you?
	• What were your reactions when you were told that you have TB? • What were your concerns then?
Perception of care received	• What were your expectations from such care? • Did you receive the expected care? • What were the positive things about the care that you received? • What were the negative things?
Gender difference (for women)	• Did you have any problem seeking for care for your illness?
RELATIVE	
Recognition of symptoms:	• How long have your relative been ill with TB? • Do you remember the time when he/she first fell ill for this disease? • What makes him/her realise that he/she was not well? • What were the signs and symptoms at that time? • What makes you realise that he/she was not well?
Health seeking behaviour /pattern	• What did you do? Did you follow the advice given?
Perception of illness	• What did you think cause the illness? • What do you call this illness in your language? • What causes you to get this illness?
Perception of care	• What were your expectations from such care?

received	• Do you think he/she receive the expected care? • What were the positive things about the care that he/she received? • What were the negative things?
Effect on patient, family/relatives	• How does this disease affect the patient? • How does this disease affect you/ the family? • What changes have you seen in the patient? • What changes have taken place in the family and household as a result of the illness?
HEALTH STAFF	
Perception of illness	• What do you think cause the illness? • What do the people here call this illness? • What causes people to get this illness?
Health seeking behaviour /pattern	• What do you think a patient will do when he/she develop this illness?
Perception of care received	• Do you think he/she receive the expected care?
Perception of delay	• Why do you think a patient delay in seeking treatment?
TRADITIONAL HEALER	
Frequency and perspectives on the cause of illness	• What is the disease known to the patient/community? • How frequent do you see such illness? • What did you think cause the illness? • What do you call this illness in your language? • What causes one to get this illness? /How can one get this illness?
Treatment	• How does one get cure from the disease? • How can one protect oneself from getting the disease?
	• Can you relate to me how you treat a client of yours who had TB?
VILLAGE HEADMAN	
Health and diseases	• What health problems commonly affect the community? • Do you have any TB patients in the community?
Perception of illness	• What is the disease known to the patient/community? • What did you think cause the illness? • What do you call this illness in your language? • What causes one to get this illness? / How can one get this illness?
Community reaction	• What is often the reaction within the community towards someone who is infected with TB? • Why is there such a reaction?

Appendix 4: PATIENT INFORMATION SHEET (FOR TB PATIENTS)

[PHASE 1]

The following section must be read by the research assistants to the participants in a language they understand well.

Principal Investigator: Christina Rundi (Hand Phone number: 019-5839528)
Co-Investigator:
Dr. Mohd. Yusof Ibrahim, Deputy Director, Sabah Health Department

Dr. Punam Mangtani, Senior Lecturer
Dr. Katherine Fielding, Senior Lecturer
London School of Hygiene and Tropical Medicine

TITLE OF RESEARCH:
Factors prolonging the time from onset of symptoms to start of treatment among smear positive TB patients in Sabah, East Malaysia.

THE NATURE AND PURPOSE OF THE STUDY:
We are doing a research study on tuberculosis (TB) and would like to invite you to take part. This study is supervised by the Sabah Health Department and the London School of Hygiene and Tropical Medicine and approved by the Ministry of Health.

STUDY DESCRIPTION
Tuberculosis is a major health problem in Sabah. The purpose of this study is to find out what problems are faced by TB patients concerning their illness from the time it started until they are put onto treatment. The results of this study will inform the Sabah Health Department and the Ministry of Health on how to make the current TB Control programme more effective.

If you decide to participate in this study, you will be one of 16 participants. It will involve an interview that will take place at a private room. Interview will be conducted by the principal investigator. The maximum length of time of your participation in this study will be about 1 - 1.5 hours in the form of an interview and will be tape recorded. The interview will involve asking you to explain your experiences from the time you fell ill to the present, also include the choices of treatment, why such choices were made, what you thought of them and the involvement of other people in the decision making process. The interview is semi-structured and there may be questions that we might ask you in relation to your answers during the interview.

If necessary, however, the study may be stopped or you may withdraw from the study at any time. If you do not wish to have the interview tape recorded please do let us know. We also seek your permission to collect some details from your clinical records.

RISK OF STUDY PARTICIPATION
There is no obvious risk to you in participating in this study. However, we hope that you will let us know if you feel stressed or emotionally or psychologically affected by the interview so that we can stop the interview or, if needed, refer you for appropriate help or support.

VOLUNTARY PARTICIPATION
Your participation in this study is voluntary and that if you decide not to participate, you will experience no loss of benefits in terms of medical care. If you decide to participate, you may change your mind about being in the study and may stop at any time. However, you should inform the interviewer of this decision immediately. Such a decision on your part will not influence the availability of future medical care.

CONFIDENTIALITY
All information provided by you will only be known to the interviewer and principal investigator. Any reference to you in person will be removed and your name will not appear on the transcripts or final report.

FORM C-1

PATIENT CONSENT FORM

This form will be read out to the patient, who will then be asked to sign two copies. One copy is to be kept by the patient, the other to be filed.

- I have read, or have been read to me, in language understandable to me, the above information. The content and meaning of this information has been fully explained to me.
- I have had time and opportunity to ask questions that I have about the study and this form, and all my questions have been answered. I have read, or have been read to me, all the contents of this consent form. I voluntarily consent and offer to take part in this study. By signing this consent form, I certify that all information I have given, is true and correct to the best of my knowledge.
- I understand that I may withdraw from the study at any time without giving any reason.
- I also agree that my clinical records may be used to provide clinical and laboratory information.

Printed name of subject: _____

IC No.: _____

Signature of subject _____

Date: _____

Thumb print of subject (if applicable): _____

Printed name of witness: _____

IC No.: _____

Signature of witness: _____

Date: _____

Printed name of person explaining consent:

IC No.: _____

Signature of person explaining consent: _____

Date: _____

PATIENT INFORMATION SHEET (FOR TB PATIENTS)

[PHASE 2]

The following section must be read by the research assistants to the participants in a language they understand well.

Principal Investigator: Christina Rundi

Co-Investigator:
Dr. Mohd. Yusof Ibrahim, Deputy Director, Sabah Health Department

Dr. Punam Mangtani, Senior Lecturer
Dr. Katherine Fielding, Senior Lecturer
London School of Hygiene and Tropical Medicine

TITLE OF RESEARCH:
Factors prolonging the time from onset of symptoms to start of treatment among smear positive TB patients in Sabah, East Malaysia.

THE NATURE AND PURPOSE OF THE STUDY:
We are doing a research study on tuberculosis (TB) and would like to invite you to take part. This study is supervised by the Sabah Health Department and the London School of Hygiene and Tropical Medicine and approved by the Ministry of Health.

STUDY DESCRIPTION
Tuberculosis is a major health problem in Sabah. The purpose of this study is to find out what problems are faced by TB patients concerning their illness from the time it started until they are put into treatment. The results of this study will inform the Sabah Health Department and the Ministry of Health of how to make the current TB Control programme more effective.

If you decide to participate in this study, you will be one of 250 participants. It will involve a private interview that will take place at a private room. The maximum length of time of your participation in this study will be about 1 - 1.5 hours in the form of an interview. The interview will use a questionnaire which will involve asking you about the symptoms you had at the beginning of your disease, where and how you got treatment, what you thought of them and the involvement of other people in the decision making process. If necessary, however, the study may be stopped or you may withdraw from the study at any time. We also seek your permission to collect some details from your clinical records.

RISK OF STUDY PARTICIPATION
There is no obvious risk to you in participating in this study. However, we hope that you will communicate to us should you feel stressed or emotionally

or psychologically affected by the interview so that we will be able to refer you for support.

VOLUNTARY PARTICIPATION

Your participation in this study is voluntary and that if you decide not to participate, you will experience no loss of benefits in terms of medical care. If you decide to participate, you may change your mind about being in the study and may stop at any time. However, you should inform the interviewer of this decision immediately. Such a decision on your part will not influence the availability of future medical care.

CONFIDENTIALITY

All information provided by you will only be known to the interviewer and principal investigator. Any reference to you in person will be removed and your name will not appear on the forms but a study number and clinic number will be assigned to your form. We will store the entire questionnaire in a locked filing cabinet. We will also store information in one computer which will be protected by a password which is only known by the principal investigator.

FORM C-2

PATIENT CONSENT FORM

This form will be read out to the patient, who will then be asked to sign 2 copies. One copy is to be kept by the patient, the other to be filed.

- I have read, or have been read to me, in language understandable to me, the above information. The content and meaning of this information has been fully explained to me.
- I have had time and opportunity to ask questions that I have about the study and this form, and all my questions have been answered. I have read, or have been read to me, all the contents of this consent form. I voluntarily consent and offer to take part in this study. By signing this consent form, I certify that all information I have given, is true and correct to the best of my knowledge.
- I understand that I may withdraw from the study at any time without giving any reason.
- I also agree that my clinical records may be used to provide clinical and laboratory information.

Printed name of subject: _____

IC No.: _____

Signature of subject _____

Date: _____

Thumb print of subject (if applicable): _____

Printed name of witness: _____

IC No.: _____

Signature of witness: _____

Date: _____

Printed name of person explaining consent:

IC No.: _____

Signature of person explaining consent: _____

Date: _____

Appendix 5: Characteristics of participants

PATIENTS					
	Sex	**Age (yrs)**	**Ethnic**	**Marital status**	**Occupation**
Patient 1	Female	33	Brunei	Married	Clerk
Patient 2	Male	36	Indian	Married	Own business
Patient 3	Female	45	Bajau	Married	Housewife
Patient 4	Male	56	Chinese	Single	Unemployed
Patient 5	Male	57	Kadazan	Single	Pensioner
Patient 6	Female	58	Kadazan	Married	Housewife
Patient 7	Female	23	Rungus	Single	Unemployed
Patient 8	Male	56	Rungus	Married	Farmer
Patient 9	Female	57	Bajau	Married	Housewife
Patient 10	Male	60	Rungus	Married	Farmer
Patient 11	Male	25	Rungus	Single	Estate worker
Patient 12	Female	27	Dusun	Married	Self-employed
Patient 13	Male	34	Dusun	Married	Self-employed
Patient 14	Male	18	Murut	Single	Unemployed
Patient 15	Female	66	Dusun	Married	Housewife
Patient 16	Male	33	Dusun	Single	Unemployed
Patient 17	Male	44	Dusun	Married	Farmer
RELATIVES, SPOUSES, NEIGHBOURS & OTHER KEY INFORMANTS					
	Sex	**Age (yrs)**	**Ethnic**	**Marital status**	**Occupation**
Non patient 1	Female	45	Rungus	Married	Housewife
Non patient 2	Female	46	Rungus	Married	Housewife
Non patient 3	Female	55	Rungus	Married	Traditional healer
Non patient 4	Male	65	Bajau	Married	Farmer
Non patient 5	Male	56	Bajau	Married	Self-employed
Non patient 6	Female	55	Bajau	Married	Housewife
Non patient 7	Male	27	Bajau	Married	Fisherman
Non patient 8	Female	45	Rungus	Married	Housewife

Non patient 9	Female	47	Rungus	Married	Housewife
Non patient 10	Female	50	Rungus	Married	Housewife
Non patient 11	Male	47	Rungus	Married	Farmer
Non patient 12	Female	52	Rungus	Married	Housewife
Non patient 13	Female	55	Rungus	Married	Traditional Healer
Non patient 14	Male	54	Sungai	Married	Farmer/Village head
Non patient 15	Female	46	Murut	Married	Cleaner

Appendix 6: Details of interview schedule

Date	Place/District	*Number	Date	District/place	*Number
3.12.05	Kota Kinabalu (KK) Putatan	1 1	23.2.06	Tuaran	4
5.12.05	Penampang	2	27.2.06	Kudat	3
6 - 7.12.05	Luyang, KK	6	2.3.06	Penampang	4
8.12.05	Inanam, KK	5	3.3.06	Inanam, KK	1
9.12.05	Menggatal, KK	3		Likas, KK	1
12.12.05	Putatan	1	7.3.06	Menggatal, KK	7
13.12.05	Papar	5	8 - 10.3.06	Ranau	9
14.12.05	Tuaran	6	14.3.06	Luyang, KK	1
15 -16.12.05	Kota Marudu	6	16.3.06	Inanam, KK	4
19 - 20.12.05	Keningau	11	20 .3.06	Kudat	9
21.12.05	Penampang	2	21.3.06	Kudat	4
11.1.06	Penampang	6		Kota Marudu	3
12 - 13.1.06	Luyang, KK	2	22.3.06	Pitas	5
16.1.06	Luyang, KK	1		Kota Marudu	4
	Menggatal, KK	1	23 - 24.3.06	Kota Marudu	8
17.1.06	Papar	8	29.3.06	Luyang, KK	1
18.1.06	Beaufort	9	31.3.06	Kota Kinabalu	1
19 - 20.1.06	Ranau	5	3 - 4.4.06	Keningau	13
23.1.06	Tuaran	7	5.4.06	Sook, Keningau	1
	Kudat	10	6.4.06	Papar	8
24.1.06	Pitas	2		Beaufort	3
	Kota Marudu	1	7.4.06	Beaufort	2
25.1.06	Kota Marudu		10.4.06	Menggatal, KK	2
26 - 27.1.06	Keningau	2	12.4.06	Telipok, KK	3
3.2.06	Luyang, KK	10		Likas, KK	1
	Inanam, KK	2	13.4.06	Tuaran	1
	Penampang	2	17.4.06	Kudat	3
6.2.06	Telipok, KK	3	18.4.06	Pitas	2
	Menggatal, KK	3		Kota Marudu	3
	Luyang, KK	5	19.4.06	Luyang, KK	2
7.2.06	Luyang, KK	5	20.4.06	Luyang, KK	2
8.2.06	Luyang, KK			Ranau	1
	Bukit Padang, KK	1	21.4.06	Keningau	1
9.2.06	Luyang, KK	3		Luyang, KK	1
13.2.06	Luyang, KK	7		Sook	2
15.2.06	Papar	2	24.4.06	Inanam, KK	3
	Luyang, KK	1		Tamparuli, Tuaran	1
16.2.06	Luyang, KK	5	25.4.06	Luyang, KK	1
20.2.06	Kinarut, Papar	3		Putatan	1
21.2.06	Luyang, KK	1	26.4.06	Tuaran	4
22.2.06	Beaufort	4	27.4.06	Luyang, KK	2

* Number interviewed

Appendix 7: Questionnaire

SABAH HEALTH DEPARTMENT
STUDY ON TIME PERIOD (2005)

1. Place of interview

1	☐	TB Chest Clinic
2	☐	Health Centre
3	☐	Hospital Ward
4	☐	Patient's home
5	☐	Others (specify) ☐

2. Respondent ID ☐☐☐

3. Interviewer ID ☐☐

4. Date of interview Day ☐☐ Month ☐☐ Year ☐☐☐☐

5. Informed consent for interview signed

0	☐	Unknown
1	☐	Yes
2	☐	No
9	☐	Refused

DATA ENTRY INFORMATION

6. First entry Day ☐☐ Month ☐☐ Year ☐☐☐☐

6.1 ID of person entering data ☐☐

7. Second entry Day ☐☐ Month ☐☐ Year ☐☐☐☐

7.1 ID of person entering data ☐☐

INTRODUCTION

CONFIDENTIAL – Tear off this page and send to PI

SOCIO-DEMOGRAPHIC INFORMATION

1. What is your full name?

2. Identification number

3. What is your home address? (give landmark if house has no number)

4. How old are you? (in years) ☐☐

5. Sex

1 ☐ Male
2 ☐ Female

6. Ethnic group

1 ☐ Kadazan
2 ☐ Dusun
3 ☐ Murut
4 ☐ Bajau
5 ☐ Malay
6 ☐ Chinese
7 ☐ Others (specify) ☐

7. Type of residence:

7.1 House

1 ☐ Village house
2 ☐ Residential area
3 ☐ Squatter area
4 ☐ Estate house (plantation)
5 ☐ Long house
6 ☐ Shared quarters
7 ☐ Quarters
8 ☐ Others (specify) ☐

7.2 Institution

9 ☐ Psychiatric Institution [Go to Q.8]
10 ☐ Prison [Go to Q.8]
11 ☐ Rehabilitation centre [Go to Q.8]
12 ☐ Senior citizen home [Go to Q.8]
13 ☐ Hostel [Go to Q.8]
14 ☐ Others (specify) ☐

7.3 How many bedrooms are there in the house? ☐

7.4 How many people are staying in the same house? ☐

8. Location of residence:

1 Urban
2 Rural

9. Education level:

1 ☐ None
2 ☐ Primary
3 ☐ Secondary
4 ☐ Form 6/Diploma/Certificate
5 ☐ Degree
6 ☐ Others (specify)

10. Marital status:

1 ☐ Single
2 ☐ Married
3 ☐ Separated
4 ☐ Divorced
5 ☐ Widowed
9 ☐ Refused

11.1 Main occupation [respondent]

1	☐	None	7	☐	Farmer
2	☐	Student	8	☐	Fisherman
3	☐	Housewife	9	☐	Retired
4	☐	Unskilled labour	10	☐	Government servant
5	☐	Skilled labour	11	☐	Professional
6	☐	Trade/business	12	☐	Others (specify) ☐

11.1 Main occupation [Head of household]

1	☐	None	7	☐	Farmer
2	☐	Student	8	☐	Fisherman
3	☐	Housewife	9	☐	Retired
4	☐	Unskilled labour	10	☐	Government servant
5	☐	Skilled labour	11	☐	Professional
6	☐	Trade/business	12	☐	Others (specify) ☐

12. Income per month [respondent]:

1	☐	No fixed income	4	☐	RM 1000-RM 3000
2	☐	< RM 500	5	☐	> RM 3000
3	☐	RM 500 - RM 999	9	☐	Refused

13. Income per month [household:

1	☐	No fixed income	4	☐	RM 1000-RM 3000
2	☐	< RM 500	5	☐	> RM 3000
3	☐	RM 500 - RM 999	9	☐	Refused

14. Do you own any of the following?

14.1	House	1	☐	Yes	2	☐	No	9 ☐ Refused
14.2	Car/boat/other transport	1	☐	Yes	2	☐	No	9 ☐ Refused
14.3	Land for farming	1	☐	Yes	2	☐	No	9 ☐ Refused
14.4	Animals	1	☐	Yes	2	☐	No	9 ☐ Refused
14.5	Television	1	☐	Yes	2	☐	No	9 ☐ Refused
14.6	Radio	1	☐	Yes	2	☐	No	9 ☐ Refused

MEDICAL HISTORY

15. Before this illness, did you suffer from any conditions that limited your ability to get around? [Example: visit friends, get to the clinic, and perform basic activities such as getting water/wood]

1 ☐ Yes
2 ☐ No

16. Do you have any medical condition as told by a doctor?

1 ☐ Yes [Go to Q.17]
2 ☐ No [Go to Q.18]
3 ☐ Don't know [Go to Q.18]

17. If yes, what kind of condition?

17.1	Diabetes	1		Yes	2		No	3		Don't know
17.2	Renal failure	1		Yes	2		No	3		Don't know
17.3	Cancer	1		Yes	2		No	3		Don't know
17.4	Asthma	1		Yes	2		No	3		Don't know
17.5	Chronic Obstructive pulmonary disease	1		Yes	2		No	3		Don't know
17.6	HIV/AIDS	1		Yes	2		No	3		Don't know
17.7	Taking immunosuppressive drugs	1		Yes	2		No	3		Don't know
17.8	Others (specify)	1		Yes	2		No	3		Don't know

18. History of TB in the family?

1 ☐ Yes [Go to Q.19]
2 ☐ No [Go to Q.20]
3 ☐ Don't know [Go to Q.20]

19. When was the most recent episode of TB in your family?

☐ Months ago
98 ☐ Not sure

20. What is the nearest private or public health facility from your home?

21. How do you get to this facility?

1 ☐ Walk
2 ☐ Own car
3 ☐ Own boat
4 ☐ Public car/bus
5 ☐ Public boat
6 ☐ Others (specify)

22. In general, how long does it take you to reach this facility?

0 ☐ Unknown
1 ☐ < 15 min
2 ☐ 15 – 29 min
3 ☐ 30 – 59 min
4 ☐ 1 – 2 hrs
5 ☐ > 2 hrs
9 ☐ Refused

23. What is the nearest hospital from your home?

24. How do you get to this hospital?

1 ☐ Walk
2 ☐ Own car
3 ☐ Own boat
4 ☐ Public car/bus
5 ☐ Public boat
6 ☐ Others (specify)

25. In general, how long does it take you to reach this hospital?

0 ☐ Unknown
1 ☐ < 15 min
2 ☐ 15 – 29 min
3 ☐ 30 – 59 min
4 ☐ 1 – 2 hrs
5 ☐ > 2 hrs
9 ☐ Refused

26. Have you ever use the services in the clinic or hospital?

1 ☐ Yes [Go to Q.27]
2 ☐ No [Go to Q.28]

27. How often did you use their services in the past year? ☐

28. What was the reason you did not use their services during the past year? [You may tick more than 1 response]

1 ☐ Not sick
2 ☐ Prefer other form of treatment (private clinic, traditional healer
3 ☐ Not so good experience in the past [Go to Q.28.1]
4 ☐ Obstacles in getting treatment [Go to Q.28.2]
5 ☐ Others (specify) ☐

28.1 Please share your experience.

☐

28.2 What was the most significant obstacle you face in getting treatment?

1 ☐ Distance to clinic
2 ☐ Financial
3 ☐ Transportation
4 ☐ Too busy
5 ☐ Do not want to leave work/children
6 ☐ Others (specify)

29. If you fall ill, where is the first place you seek treatment?

1 ☐ Government clinic
2 ☐ Private clinic
3 ☐ Traditional healer
4 ☐ Depends on the illness [explain] ☐
5 ☐ Others (specify) ☐

SYMPTOMS

30. Tuberculosis can affect people in different ways and over time the symptoms can change. People are often treated for other conditions like malaria or typhoid before the correct diagnosis of tuberculosis is made. Can you think back to when you first got sick and tell me about the first symptoms you noticed (for example: cough, fever, weight loss) -Maximum 3 responses.

30.1 Respiratory

Cough	1		Yes	2		No
Breathlessness	1		Yes	2		No
Chest Pain	1		Yes	2		No
Coughing blood	1		Yes	2		No
Hoarseness	1		Yes	2		No

30.2 Constitutional

Fever	1		Yes	2		No
Loss of appetite	1		Yes	2		No
Loss of weight	1		Yes	2		No
Insomnia	1		Yes	2		No
Fatigue/lethargy	1		Yes	2		No

31. How long ago did you first notice these symptoms?

Day | Month | Year

OR

Year

OR

Month

OR

[ ] Cannot recall

32. Did you seek help because of these symptoms?

1 [ ] Yes
2 [ ] No [Go to Q.34]

32.1 How long after you have decided to seek treatment before you actually went? [ ] days

33. What particular symptoms first led you to seek care outside your home? [Maximum 3 responses]

33.1 Respiratory

1 [ ] Cough
2 [ ] Breathlessness
3 [ ] Chest pain
4 [ ] Coughing blood
5 [ ] Hoarseness

33.2 Constitutional

1 [ ] Fever
2 [ ] Loss of appetite
3 [ ] Loss of weight
4 [ ] Insomnia
5 [ ] Fatigue/lethargy

34. After you noticed the symptom(s) above, how long did you wait before seeking help?

☐ Days
☐ Months
98 ☐ Not sure

HEALTH CARE UTILISATION

35. Where did you first go for treatment?

1 ☐ Unknown
2 ☐ Pharmacy
3 ☐ Public/Govt. Doctor
4 ☐ Private Doctor
5 ☐ Traditional healer
9 ☐ Refused

36. Do you recall the specific or approximate date of this visit?

Day ☐☐ Month ☐☐ Year ☐☐☐☐

OR

Year ☐☐☐☐

OR

Month ☐☐

OR

☐ Cannot recall

37. What is the main reason(s) you chose this place? [Maximum 3 responses]

0 ☐ Unknown
9 ☐ Refused
1 ☐ Near to home
2 ☐ Good reputation
3 ☐ Pleasant staff
4 ☐ Strong medicine
5 ☐ Suggested by friends, relatives
6 ☐ Always go there
7 ☐ Referred by health provider
8 ☐ Belief in the treatment
10 ☐ No other choice
11 ☐ Others (specify) ☐

38. How do you get to this place?

1 ☐ Walk
2 ☐ Own car
3 ☐ Own boat
4 ☐ Public car/bus
5 ☐ Public boat
6 ☐ Others (specify) ☐

39. How long does it take you to reach this place?

0 ☐ Unknown
1 ☐ < 15 min
2 ☐ 15 – 29 min
3 ☐ 30 – 59 min
4 ☐ 1 – 2 hrs
5 ☐ > 2 hrs
9 ☐ Refused

40. What health problem did they say you have?

☐

41. By what name did they call it? [specific, summary or short description in patient's words]

42. Overall did this provider and the staff have a good attitude and treated you with respect?

1 ☐ Yes
2 ☐ No
9 ☐ Refused

43. Was there more than 1 encounter?

1 ☐ Yes
2 ☐ No

44. Besides the above, where as did you seek treatment?

0 ☐ None
9 ☐ Refused
1 ☐ Pharmacy
2 ☐ Public/Govt Doctor
3 ☐ Private Doctor
4 ☐ Traditional Healer
5 ☐ Local Herbalist
6 ☐ Others (specify)

[NOTE: Q. 45 & 46, to be asked to those who seek treatment other than govt facility]

45. Why did you visit the government health clinic?

0 ☐ Unknown
9 ☐ Refused
1 ☐ Referred by other provider
2 ☐ Symptoms worsened
3 ☐ Suggested by friends, relatives
4 ☐ Others (specify)

46. Do you recall the specific or approximate date of this visit?

Day ☐☐ Month ☐☐ Year ☐☐☐☐

OR

Year ☐☐☐☐

OR

Month ☐☐

OR

☐ Cannot recall

47. How many encounters were at government health facilities before diagnosis of TB was made? ☐

47.1 Please list the clinic.

47.2 Were you referred to the hospital for further investigation?

1 ☐ Yes 2 ☐ No

47.3 Where was the diagnosis of TB made?

☐

47.4 Were you admitted to the ward after diagnosis?

1 ☐ Yes 2 ☐ No

EXAMINATION

48. Were you asked to give sputum sample?

1 ☐ Yes [Go to Q.49.3]
2 ☐ No [Go to Q. 49.1]

49.1 At which visit was sputum sample requested?

☐ Visit [Go to Q.49.3]
☐ None at all [Go to Q. 49.2]
☐ Can't remember [Go to Q.49.3]

49.2 At which clinic was sputum sample requested?

☐

49.3 How many specimens were you asked to give, in total? ☐

50. Did you have any problem providing all requested sputum specimen?

1 ☐ Yes [Go to Q.51]
2 ☐ No [Go to Q. 52]
☐ Can't remember [Go to Q.52]
9 ☐ Refused [Go to Q. 52]

51. Please give the reason.

1 ☐ Felt better
2 ☐ Felt embarrassed
3 ☐ Forgetfulness
4 ☐ No transport
5 ☐ Long waiting time at the clinics
6 ☐ Could not leave work or responsibilities
7 ☐ Concerned about loss of wages
8 ☐ Not concern/indifferent
10 ☐ Financial constraint
11 ☐ Others (specify)
☐

52. How many days did it take you to complete sending all the specimens? ☐

53. What was the reason for the delay?

0 ☐ Unknown
97 ☐ Not applicable
9 ☐ Refused
1 ☐ Earliest appointment date
2 ☐ Could not take time off at home and/or work
3 ☐ Family concerns
4 ☐ Physically unable
5 ☐ No transport
6 ☐ Fear of diagnosis
7 ☐ Not concern/indifferent
8 ☐ Financial constraint
10 ☐ Others (specify) _____

54. Did the provider request that you have a chest x-ray done?

1 ☐ Yes [Go to Q.55]
2 ☐ No [Go to Q. 60]
☐ Can't remember [Go to Q.60]
9 ☐ Refused [Go to Q. 60]

55. Did you have a chest x-ray done?

1 ☐ Yes [Go to Q.57]
2 ☐ No [Go to Q. 56]
☐ Can't remember [Go to Q.60]
9 ☐ Refused [Go to Q. 60]

56. If No, why didn't you have the X-ray?

0 ☐ Unknown
97 ☐ Not applicable
9 ☐ Refused
1 ☐ Earliest appointment date
2 ☐ Could not take time off at home and/or work
3 ☐ Family concerns
4 ☐ Physically unable
5 ☐ No transport
6 ☐ Fear of diagnosis
7 ☐ Not concern/indifferent
8 ☐ Financial constraint
10 ☐ Others (specify) _____

57. How many days did it take you to get a chest x-ray done from the time it was requested? ☐

58. What was the reason for the delay?

0 ☐ Unknown
97 ☐ Not applicable
9 ☐ Refused
1 ☐ Earliest appointment date
2 ☐ Could not take time off at home and/or work
3 ☐ Family concerns
4 ☐ Physically unable
5 ☐ No transport
6 ☐ Fear of diagnosis
7 ☐ Not concern/indifferent
8 ☐ Financial constraint
10 ☐ Others (specify) _____

59. How many x-rays were done before diagnosis was made? ☐

PATIENT'S KNOWLEDGE AND PERCEPTION OF TB

60. Have you heard of TB before your illness?

1 ☐ Yes [Go to Q.60.1]
2 ☐ No [Go to Q. 61]
9 ☐ Refused [Go to Q. 61]

60.1 Please state what you have heard about TB.

61. What do you think is the cause of TB?

0 ☐ Don't know
9 ☐ Refused
1 ☐ germ
2 ☐ hereditary
3 ☐ poverty
4 ☐ superstitious beliefs
5 ☐ dietary
6 ☐ worry/depression
7 ☐ alcohol
8 ☐ Dirty environment
10 ☐ Dust
11 ☐ Contaminated food
12 ☐ Gastric pain
13 ☐ smoking
14 ☐ hard work
15 ☐ fate
16 ☐ cold/wet condition
17 ☐ Others (specify)

62. In your opinion, is TB infectious?

1 ☐ Yes
2 ☐ No
☐ Don't know
9 ☐ Refused

62.1 How does it spread?

☐ Don't know
9 ☐ Refused
1 ☐ From an infected person
2 ☐ hereditary
3 ☐ Eating together
4 ☐ Talking face to face
5 ☐ Others (specify)

63. Do you think that with treatment, someone with TB can be completely cured?

1 ☐ Yes [please elaborate]
2 ☐ No [please elaborate]
☐ Don't know
9 ☐ Refused

64. TB can affect its patient's lives in many ways. How has TB affected your life?

PHYSICAL

FINANCIAL

EMOTIONAL

SOCIAL

LIFE PRACTICE

64.1 In your opinion, is it a disgrace to get TB?

1 Yes [please elaborate]

2 No [please elaborate]

Don't know

9 Refused

64.2 In your opinion, should a TB patient be isolated from other people?

1 Yes [please elaborate]

2 No [please elaborate]

Don't know

9 Refused

64.3. In your opinion, should a TB patient be invited to any social gathering?

1 Yes [please elaborate]

2 No [please elaborate]

Don't know

9 Refused

64.4. In your opinion, can a single person with TB marry?

1		Yes [please elaborate]
2		No [please elaborate]
		Don't know
9		Refused

65.1. If someone has TB, he/she avoids talking about it with other persons.

1 Very strongly disagree	2 Strongly Disagree	3 Disagree	4 Agree	5 Strongly agree	6 Very strongly agree

65.2. If a young person catches TB, he/she will experience the consequences for the rest of his/her life.

1 Very strongly disagree	2 Strongly Disagree	3 Disagree	4 Agree	5 Strongly agree	6 Very strongly agree

65.3. It is difficult to earn your living after recovering from TB.

1 Very strongly disagree	2 Strongly Disagree	3 Disagree	4 Agree	5 Strongly agree	6 Very strongly agree

65.4. People who are treated for TB, should talk to others about it.

1 Very strongly disagree	2 Strongly Disagree	3 Disagree	4 Agree	5 Strongly agree	6 Very strongly agree

65.5. After recovering from TB, everyone treats you in the same way as before.

1 Very strongly disagree	2 Strongly Disagree	3 Disagree	4 Agree	5 Strongly agree	6 Very strongly agree

66.6. It is a disgrace for the family to have a family member with TB.

1 Very strongly disagree	2 Strongly Disagree	3 Disagree	4 Agree	5 Strongly agree	6 Very strongly agree

66.7. Even your best friends sometimes desert you when you have an infectious disease, like TB.

1 Very strongly disagree	2 Strongly Disagree	3 Disagree	4 Agree	5 Strongly agree	6 Very strongly agree

PERCEPTION OF HEALTH SERVICES

66. Overall, how convenient or inconvenient was it for you to reach the facility?

1 ☐ Convenient [Go to Q.68]
2 ☐ Inconvenient [Go to Q. 67]
9 ☐ Refused [Go to Q. 68]

67. What made this process difficult or inconvenient? (Maximum 3 responses)

0 ☐ Don't know
9 ☐ Refused
1 ☐ Travel time to health facility
2 ☐ Waiting time
3 ☐ Clinic hours
4 ☐ Staff attitude
5 ☐ Lack of privacy
6 ☐ Staff knowledge
7 ☐ Numerous visits
8 ☐ Finding out results
10 ☐ Return visit to HCP for follow up
11 ☐ Others (specify) _____

68. What was your perception of the health facility before you went there for treatment?

0 ☐ Unknown
9 ☐ Refused
1 ☐ Excellent
2 ☐ Good
3 ☐ Moderate
4 ☐ Poor
5 ☐ Very poor
6 ☐ Neutral

69. What is your perception of the health facility after you have been diagnosed and started on treatment?

0 ☐ Unknown
9 ☐ Refused
1 ☐ Excellent
2 ☐ Good
3 ☐ Moderate
4 ☐ Poor
5 ☐ Very poor
6 ☐ Neutral

70. How would you rate the following? [Scale of 1-5, 5 being the highest]

☐ Staff knowledge on diagnosis
☐ Staff attitude
☐ Waiting time for consultation
☐ Waiting time for sputum examination
☐ Waiting time for results

OTHERS

71. Have you consume alcohol in the past?

1 ☐ Yes [Go to Q.72]
2 ☐ No [Go to Q. 75]
9 ☐ Refused [Go to Q. 75]

72. Do you still consume alcohol?

1 ☐ Yes [Go to Q.73]
2 ☐ No [Go to Q. 75]
9 ☐ Refused [Go to Q. 75]

73. How often do you consume alcohol?

9	☐	Refused	
1	☐	Everyday	
2	☐	> 2 times a week	
3	☐	once a week	
4	☐	> once a month	
5	☐	once in several months	
6	☐	once a year	

74. How much do you consume each time?

9	☐	Refused
1	☐	About a glass
2	☐	2- 3 glasses each time
3	☐	≥ 4 glasses each time

75. Have you smoke in the past?

1	☐	Yes [Go to Q.76]
2	☐	No [Go to Q. 78]
9	☐	Refused [Go to Q. 78]

76. Do you still smoke?

1	☐	Yes [Go to Q.77]
2	☐	No [Go to Q. 78]
9	☐	Refused [Go to Q. 78]

77. On average, how many cigarettes do you smoke a day? ☐

78. Have you ever been involved with drugs?

1	☐	Yes
2	☐	No
9	☐	Refused

Thank you very much for your cooperation.

DATA ABSTRACTION SHEET

Respondent ID: ☐☐☐

1. Date of diagnosis

Day	Month	Year
☐☐	☐☐	☐☐☐☐

2. Smear results

2.1 First specimen

Day	Month	Year
☐☐	☐☐	☐☐☐☐

Day	Month	Year
☐☐	☐☐	☐☐☐☐

1 ☐ Positive
2 ☐ Negative
3 ☐ Inconclusive
4 ☐ Not done
5 ☐ Not sent by patient
6 ☐ Result lost

2.2 Second specimen

Day ☐☐ Month ☐☐ Year ☐☐☐☐

1 ☐ Positive
2 ☐ Negative
3 ☐ Inconclusive
4 ☐ Not done
5 ☐ Not sent by patient
6 ☐ Result lost

2.3 Third specimen

Day ☐☐ Month ☐☐ Year ☐☐☐☐

1 ☐ Positive
2 ☐ Negative
3 ☐ Inconclusive
4 ☐ Not done
5 ☐ Not sent by patient
6 ☐ Result lost

2.4 More than 3 specimens taken

1 ☐ Yes
2 ☐ No

2.5 How many sputum samples were taken and examined? ☐

3. Other investigations

3.1 Chest x-ray

Day ☐☐ Month ☐☐ Year ☐☐☐☐

1 ☐ Yes
2 ☐ No

3.1.1 How many times was chest x-ray performed? ☐

3.2 Sputum culture

1 ☐ Yes [Go to 3.2.1]
2 ☐ No [Go to 4]

3.2.1 Date sent:

Day	Month	Year

3.2.2 Date of result:

Day	Month	Year

3.2.3 Result:

4. Treatment initiation date

Day	Month	Year

5. Height: (cm)

6. Weight: (kg)

Abstracted by:

Date:

Day	Month	Year

Appendix 8: Results of univariate analysis for patient delay of more than 90 days.

a. Univariate analysis of socio-demographic and social history factors (distal determinants) and patient delay of more than 90 days (n=272)

Covariate	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Location						
Urban	59 (21.7)	50	9 (15.2)	1		
Rural	213 (78.3)	158	55 (25.8)	1.93	0.89 - 4.21	0.09
Sex						
Male	172 (63.9)	133	39 (22.7)	1		
Female	100 (36.1)	75	25 (25)	1.13	0.64 - 2.02	0.66
Age group (years)						
18 - 29	82 (30.1)	67	15 (18.3)	1		
30 - 39	51 (18.8)	36	15 (29.4)	1.86	0.82 - 4.24	
40 - 49	55 (20.2)	45	10 (18.2)	0.99	0.41 - 2.40	
50 - 59	38 (14)	24	14 (36.8)	2.60	1.10 - 6.19	
60 - 88	46 (16.9)	36	10 (21.7)	1.24	0.51 - 3.04	0.16
Race						
KDM	128 (47.1)	96	32 (25)	1		
Bajau	48 (17.6)	40	8 (16.7)	0.6	0.25 - 1.41	
Other indigenous	73 (26.8)	56	17 (23.3)	0.91	0.46 - 1.79	
Chinese	14 (5.2)	10	4 (28.6)	1.2	0.35 - 4.09	
Others	9 (3.3)	6	3 (33.3)	1.5	0.35 - 6.35	0.71
Marital status						
Single	62 (22.8)	46	16 (25.8)	1		
Married	186 (68.4)	146	40 (21.5)	0.79	0.40 - 1.53	
Others	24 (8.8)	16	8 (33.3)	1.44	0.52 - 3.99	0.41
Education (n_{miss}=1)						
None	56 (20.7)	41	15 (26.8)	1		
Primary	96 (35.4)	75	21 (21.9)	0.76	0.36 - 1.64	
Secondary	99 (36.5)	75	24 (24.2)	0.87	0.41 - 1.85	
Tertiary & above	20 (7.4)	16	4 (20)	0.68	0.20 - 2.37	0.89
Household income (n_{miss}=8)						
No fixed income	17 (6.4)	12	5 (29.4)	1		
< USD 132	73 (27.7)	55	18 (24.7)	0.78	0.24 - 2.53	
USD 132 - 263	82 (31.1)	66	16 (19.5)	0.58	0.18 - 1.89	
> USD 263	92 (34.8)	70	22 (23.9)	0.75	0.24 - 2.38	0.77
Own house						
No	98 (36)	79	19 (19.4)	1		
Yes	174 (64)	129	45 (25.9)	1.45	0.79 - 2.66	0.22
Own transport						
No	179 (65.8)	138	41 (22.9)	1		
Yes	93 (34.2)	70	23 (24.7)	1.11	0.62 - 1.99	0.74
Own Land(n_{miss}=1)						
No	131 (48.3)	98	33 (25.2)	1		
Yes	140 (51.7)	110	30 (21.4)	0.81	0.46 - 1.42	0.46
Livestock						
No	175 (64.3)	139	36 (20.6)	1		

Covariate	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Yes	97 (35.7)	69	28 (28.9)	1.57	0.88 - 2.78	0.12
TV/radio(n_{miss}=4)						
No	41 (15.3)	31	10 (24.4)	1		
Yes	227 (84.7)	173	54 (23.8)	0.97	0.44 - 2.10	0.93
Type of house						
'Village'	215 (79)	158	57 (26.5)	1		
Residential	29 (10.7)	27	2 (6.9)	0.20	0.05 - 0.89	
Others	28 (10.3)	23	5 (17.9)	0.60	0.22 - 1.66	0.03
Alcohol intake (n_{miss}=1)						
Never	98 (36.2)	80	18 (18.4)	1		
Past intake	140 (51.7)	102	38 (27.1)	1.65	0.88 - 3.12	
Current	33 (12.2)	25	8 (24.2)	1.42	0.55 - 3.66	0.28
History of smoking (n_{miss}=1)						
Never	114 (42.1)	91	23 (20.2)	1		
Ex-smoker	121 (44.6)	90	31 (25.6)	1.36	0.74 - 2.51	
Current	36 (13.3)	26	10 (27.8)	1.52	0.64 - 3.60	0.50
Past history of drug abuse (n_{miss}=1)						
No	254 (93.7)	195	59 (23.2)	1		
Yes	17 (6.3)	12	5 (29.4)	1.38	0.46 - 4.08	0.56

* p-value from likelihood ratio test

b. Univariate analysis of medical and family history factors (intermediate determinants) and patient delay of more than 90 days

Covariate	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Mobility problem						
No	239 (87.9)	182	57 (23.9)	1		
Yes	33 (12.1)	26	7 (21.2)	0.86	0.35 - 2.09	0.74
Co-morbidity						
No	184 (67.7)	148	36 (19.6)	1		
Yes	88 (32.3)	60	28 (31.8)	1.92	1.07 - 3.44	0.03
Family history of TB (n_{miss}=1)						
No	132 (48.7)	100	32 (24.2)	1		
Yes	139 (51.3)	107	32 (23.0)	0.93	0.53 - 1.64	0.81

* p-value from likelihood ratio test

c. Univariate analysis of health care utilisation factors and patient delay of more than 90 days

Covariate	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
Ever use government health facility						
No	42 (15.4)	31	11 (26.2)	1.18	0.56 - 2.52	
Yes	230 (84.6)	177	53 (23.0)	1		0.66
Number of times used over past year (n_{miss}=3)						
Never use	42 (15.6)	31	11 (26.2)	1		
None	49(18.2)	38	11 (22.5)	0.82	0.31 - 2.13	
1 - 2 times	65 (24.2)	54	11 (16.9)	0.57	0.22 - 1.48	
3 or more	113 (42)	82	31 (27.4)	1.06	0.48 - 2.38	0.42
Travelling time to the nearest clinic (n_{miss}=2)						
< 15 min	144 (53.3)	114	30 (20.8)	1		
15 - 29 min	89 (33)	66	23 (25.8)	1.32	0.71 - 2.47	
≥ 30 min	37 (13.7)	27	10 (27)	1.41	0.61 - 3.23	0.58
Transport to the nearest clinic						
Public transport	123 (45.2)	87	36 (29.3)	1		
Own transport	101 (37.1)	82	19 (18.8)	0.56	0.30 - 1.05	
Walk	48 (17.7)	39	9 (18.8)	0.56	0.24 - 1.27	0.05
Travelling time to the nearest hospital (n_{miss}=1)						
< 15 min	49 (18.1)	39	10 (20.4)	1		
15 - 29 min	98 (36.2)	72	26 (26.5)	1.41	0.62 - 3.22	
≥ 30 min	124 (45.7)	96	28 (22.6)	1.14	0.50 - 2.56	0.67
Transport to the nearest hospital						
Public transport	164 (60.3)	122	42 (25.6)			
Own transport	102 (37.5)	80	22(21.6)			
Walk	6 (2.2)	6	0			
Usual first place for treatment (n_{miss}=1)						
Gov facility	198 (73.1)	156	42 (21.2)	1		
Others	73 (26.9)	51	22 (30.1)	1.60	0.87 - 2.94	0.12
Treatment choice (for current illness)						
Gov clinic	200 (73.5)	153	47 (23.5)	1		
Others	72 (26.5)	55	17 (23.6)	1.0	0.53 - 1.90	0.98
Travelling time to treatment choice						
< 15 min	96 (35.3)	78	18 (18.8)	1		
15 - 29 min	95 (34.9)	71	24 (25.3)	1.46	0.73 - 2.92	
≥ 30 min	81 (29.8)	59	22 (27.2)	1.62	0.79 - 3.28	0.36
Transport to						

Appendix 8: Results of univariate analysis for patient delay of more than 90 days

Covariate	n (col %)	No delay	Patient delay (row%)	OR	Confidence interval (CI)	p-value*
treatment choice						
Public transport	134 (49.3)	94	40 (29.8)	1		
Own transport	112 (41.2)	92	20 (17.9)	0.51	0.28 - 0.94	
Walk	26 (9.5)	22	4(15.4)	0.43	0.14 - 1.32	0.05

* p-value from likelihood ratio test

Appendix 9: Results of univariate analysis for doctor delay of more than 60 days

a. Univariate analysis of socio-demographic and social history factors (distal determinants) and doctor delay of more than 60 days (n=260)

Covariate	n (col %)	No delay	Doctor delay (row %)	OR	Confidence interval (CI)	p-value*
Location						
Urban	60 ()	44	16 (26.7)	1		
Rural	200 ()	153	47 (23.5)	0.84	0.44 - 1.64	0.62
Sex						
Male	166 (63.9)	125	41 (24.7)	1		
Female	94 (36.1)	72	22 (23.4)	0.93	0.51 - 1.69	0.82
Age group (years)						
18 - 29	77 (29.6)	57	20 (26)	1		
30 - 39	50 (19.2)	37	13 (26)	1.00	0.44 - 2.25	
40 - 49	54 (20.8)	41	13 (24.1)	0.90	0.40 - 2.02	
50 - 59	37 (14.2)	28	9 (24.3)	0.92	0.37 - 2.27	
60 - 88	42 (16.2)	34	8 (19.1)	0.67	0.27 - 1.69	0.93
Race						
KDM	122 (46.9)	89	33 (27.1)	1		
Bajau	46 (17.7)	35	11 (23.9)	0.85	0.39 - 1.86	
Other indigenous	69 (26.5)	53	16 (23.2)	0.81	0.41 - 1.62	
Chinese	14 (5.4)	13	1 (7.1)	0.21	0.03 - 1.65	
Others	9 (3.5)	7	2 (22.2)	0.77	0.15 - 3.90	0.49
Marital status						
Single	60 (23.1)	43	17 (28.3)	1		
Married	181 (69.6)	139	42 (23.2)	0.76	0.39 - 1.48	
Others	19 (7.3)	15	4 (21.1)	0.67	0.19 - 2.33	0.69
Education (n_{miss}=1)						
None	52 (20.1)	43	9(17.3)	1		
Primary	90 (34.8)	65	25 (27.8)	1.84	0.78 - 4.31	
Secondary	99 (38.2)	74	25 (25.3)	1.61	0.69 - 3.77	
Tertiary & above	18 (6.9)	14	4 (22.2)	1.37	0.36 - 5.13	0.54
Household income (n_{miss}=7)						
No fixed income	15 (5.9)	9	6 (40)	1		
< USD 132	71 (28.1)	56	15 (21.1)	0.40	0.12 - 1.31	
USD 132 - 263	77 (30.4)	53	24 (31.2)	0.68	0.22 - 2.12	
> USD 263	90 (35.6)	73	17 (18.9)	0.35	0.11 - 1.11	0.13
Own house						
No	167 (64.1)	126	41 (24.5)	1		
Yes	93 (35.8)	71	22 (23.7)	0.95	0.54 - 1.72	0.87
Own transport						
No	91 (35)	66	25 (27.5)	1		
Yes	169 (65)	131	38 (22.5)	1.30	0.73 - 2.34	0.37
Own Land(n_{miss}=1)						
No	133 (51.3)	102	31 (23.3)	1		
Yes	126 (48.7)	94	32 (25.4)	0.89	0.50 - 1.57	0.69
Livestock						

Appendix 9: Results of univariate analysis for doctor delay of more than 60 days

Covariate	n (col %)	No delay	Doctor delay (row %)	OR	Confidence interval (CI)	p-value*
No	90 (34.6)	66	24 (26.7)	1		
Yes	170 (65.4)	131	39 (22.9)	1.22	0.68 - 2.20	0.50
TV/radio(n_{miss}=4)						
No	219 (85.5)	164	55 (25.1)	1		
Yes	37 (14.4)	30	7 (18.9)	1.44	0.60 - 3.46	0.40
Type of house						
'Village'	204 (78.4)	87	117 (57.3)	1		
Residential	28 (10.8)	10	18 (64.3)	1.3	0.54 - 3.14	
Others	28 (10.8)	14	14 (50)	1.08	0.43 - 2.70	0.84
Alcohol intake (n_{miss}=1)						
Never	93 (35.8)	45	48 (51.6)	1		
Past intake	133 (51.1)	51	82 (61.6)	1.34	0.71 - 2.53	
Current	34 (13.1)	15	19 (55.9)	1.62	0.66 - 3.96	0.50
History of smoking (n_{miss}=1)						
Never	109 (41.9)	46	63 (57.8)	1		
Ex-smoker	116 (44.6)	50	66 (56.9)	1.06	0.58 - 1.96	
Current	35 (13.5)	15	20 (57.1)	0.94	0.38 - 2.33	0.96
Drug misuse						
No	243 (93.5)	186	57 (23.5)	1		
Yes	17 (6.5)	11	6 (35.3)	1.78	0.63 - 5.05	0.27

* p-value from likelihood ratio test

b. Univariate analysis of medical and family history (intermediate determinants) and doctor delay of more than 60 days

Covariate	n (%)	No delay	Doctor delay (%)	OR	Confidence interval (CI)	p-value*
Problem with mobility						
No	228 (87.7)	172	56 (24.6)	1		
Yes	32 (12.3)	25	7 (21.9)	0.86	0.35 - 2.10	0.74
Co-morbidity						
No	175 (67.3)	135	40 (22.9)	1		
Yes	85 (32.7)	62	23 (27.1)	1.25	0.69 - 2.27	0.46
Family history of TB (n_{miss}=1)						
No	126 (48.7)	95	31 (24.6)	1		
Yes	133 (51.3)	101	32 (24.1)	0.97	0.55 - 1.72	0.92

* p-value from likelihood ratio test

c. Univariate analysis of symptoms (proximal determinants) and doctor delay of more than 60 days

Covariate	n (col %)	No delay	Doctor delay (row %)	OR	Confidence interval (CI)	p-value*
Cough						
No	21 (8.1)	16	5(23.8)	1		
Yes	239 (91.9)	181	58 (24.3)	1.03	0.36 - 2.93	0.96
Chest pain						
No	123 (47.3)	100	23 (18.7)	1		
Yes	137 (52.7)	97	40 (29.2)	1.79	0.99 - 3.23	0.05
Shortness of breath						
No	96 (36.9)	82	14 (14.6)	1		
Yes	164 (63.1)	115	49 (29.9)	2.49	1.28 - 4.87	0.006
Hemoptysis						
No	132 (50.8)	102	30 (22.7)	1		
Yes	128 (49.2)	95	33 (25.8)	1.18	0.67 - 2.09	0.57
Loss of appetite						
No	76 (29.2)	57	19 (25)	1		
Yes	184 (70.8)	140	44 (23.9)	0.94	0.51 - 1.75	0.85
Loss of weight						
No	36 (13.8)	31	5 (13.9)	1		
Yes	224 (86.2)	166	58 (25.9)	2.17	0.80 - 5.87	0.12
Insomnia						
No	88 (33.8)	65	23 (26.1)	1		
Yes	172 (66.2)	132	40 (23.3)	0.86	0.47 - 1.55	0.61
Fever						
No	59 (22.7)	52	7 (11.9)	1		
Yes	201 (77.3)	145	56 (27.9)	2.87	1.21 - 6.78	0.01
Lethargy						
No	50 (19.2)	43	7 (14)	1		
Yes	210 (80.8)	154	56 (26.7)	2.23	0.94 - 5.29	0.06

* p-value from likelihood ratio test

d. Univariate analysis of health care utilisation (intermediate determinants) and doctor delay of more than 60 days

Covariate	n (col %)	No delay	Doctor Delay (row %)	OR	Confidence interval (CI)	p-value*
Ever use government health facility						
Yes	220 (84.6)	172	48 (21.8)	1		
No	40 (15.4)	25	15 (37.5)	2.15	1.05 - 4.40	0.04
Number of times used over past year (n_{miss}=3)						
Never use	40 (15.6)	25	15 (37.5)	1		
None	50 (19.5)	40	10 (20)	0.42	0.16 - 1.07	

Appendix 9: Results of univariate analysis for doctor delay of more than 60 days

Covariate	n (col %)	No delay	Doctor Delay (row %)	OR	Confidence interval (CI)	p-value*
1 - 2 times	61 (23.7)	53	8 (13.1)	0.25	0.09 - 0.67	
3 or more	106 (41.2)	77	29 (27.4)	0.63	0.29 - 1.35	0.03
Travel time to the nearest clinic (n_{miss}=2)						
< 15 min	140 (54.3)	102	38 (27.1)	1		
15 - 29 min	83 (32.2)	65	18 (21.7)	0.74	0.39 - 1.41	
≥ 30 min	35 (13.6)	29	6 (17.1)	0.55	0.21 -1.44	0.37
Transport to the nearest clinic						
Public transport	116 (44.6)	91	25 (21.5)	1		
Own transport	96 (36.9)	69	27 (28.1)	1.42	0.76 - 2.67	
Walk	48 (18.5)	37	11 (22.9)	1.08	0.48 - 2.42	0.53
Travel time to the nearest hospital (n_{miss}=1)						
< 15 min	46 (17.8)	38	8 (17.4)	1		
15 - 29 min	94 (36.3)	71	23 (24.5)	1.54	0.63 - 3.77	
≥ 30 min	119 (45.9)	87	32 (26.9)	1.75	0.74 - 4.14	0.42
Transport to the nearest hospital						
Public transport	157 (60.4)	119	38 (24.2)			
Own transport	97 (37.3)	72	25 (25.8)			
Walk	6 (2.3)	6	0			
Usual first choice of treatment (n_{miss}=1)						
Gov clinic	189 (73)	146	43 (22.7)	1		
Others	70 (27)	50	20 (28.6)	1.36	0.73 - 2.52	0.33
Treatment choice for current illness (TB)						
Gov clinic	189 (72.7)	149	40 (21.2)	1		
Others	71 (27.3)	48	23 (32.4)	1.78	0.97 - 3.28	0.06
Travel time to treatment choice						
< 15 min	94 (36.2)	71	23 (24.5)	1		
15 - 29 min	88 (33.8)	65	23 (26.1)	1.09	0.56 - 2.13	
≥ 30 min	78 (30)	61	17 (21.8)	0.86	0.42 - 1.76	0.80
Transport to the treatment choice						
Public transport	128 (49.2)	97	31 (24.2)	1		
Own transport	107 (41.1)	82	25 (23.4)	0.95	0.52 - 1.74	
Walk	25 (9.6)	18	7 (28)	1.22	0.46 - 3.18	0.89

* p-value from likelihood ratio test

f. Univariate analysis of health provider factors (proximal determinants) and doctor delay of more than 60 days

Covariate	n (col %)	No delay	Doctor delay (row %)	OR	Confidence interval (CI)	p-value*
Sputum exam at 1st visit						
Yes	181 (69.6)	146	35 (19.3)	1		
No	79 (30.4)	51	28 (35.4)	2.75	0.24 - 0.79	0.005
Repeat visit						
No	169 (65)	144	25 (14.8)	1		
Yes	91 (35)	53	38 (41.8)	4.13	2.21 - 7.71	<0.001
Referral made						
No	233 (89.6)	176	57 (24.5)	1		
Yes	27 (10.4)	21	6 (22.2)	0.88	0.34 - 2.30	0.80
Hospitalised						
No	200 (76.9)	153	47 (23.5)	1		
Yes	60 (23.1)	44	16 (26.7)	1.18	0.61 - 2.29	0.62

* p-value from likelihood ratio test